Bill as Introduced

HB 1326 - AS INTRODUCED

2010 SESSION

10-2200
10/01

HOUSE BILL ***1326***

AN ACT relative to the use of long-term antibiotics for the treatment of Lyme disease.

SPONSORS: Rep. Daniels, Hills 6; Rep. Vita, Straf 3

COMMITTEE: Health, Human Services and Elderly Affairs

ANALYSIS

This bill authorizes licensed physicians to prescribe long-term antibiotics for therapeutic purposes to patients diagnosed with Lyme disease.

- -

Explanation: Matter added to current law appears in ***bold italics.***
Matter removed from current law appears [~~in brackets and struckthrough.~~]
Matter which is either (a) all new or (b) repealed and reenacted appears in regular type.

HB 1326 - AS INTRODUCED

10-2200
10/01

STATE OF NEW HAMPSHIRE

In the Year of Our Lord Two Thousand Ten

AN ACT relative to the use of long-term antibiotics for the treatment of Lyme disease.

Be it Enacted by the Senate and House of Representatives in General Court convened:

1 New Section; Physicians; Treatment of Lyme Disease. Amend RSA 329 by inserting after section 31 the following new section:

329:32 Treatment of Lyme Disease. A physician licensed under this chapter may prescribe, administer, or dispense antibiotic therapy for therapeutic purposes to a person diagnosed with and having symptoms of Lyme disease if a diagnosis and treatment plan has been documented in the physician's medical record for that patient. No licensed physician may be subject to disciplinary action solely for prescribing, administering, or dispensing long-term antibiotic therapy for a patient clinically diagnosed with Lyme disease, if a diagnosis and treatment plan has been documented in the physician's medical record for that patient. In this section:

I. "Long-team antibiotic therapy" means the administration of oral, intramuscular, or intravenous antibiotics, singly or in combination, for periods of time in excess of 4 weeks.

II. "Lyme disease" means the clinical diagnosis by a licensed physician 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 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 licensed physician.

2 Effective Date. This act shall take effect 60 days after its passage.

HB 1326 – AS AMENDED BY THE HOUSE

17Feb2010... 0574h

2010 SESSION

10-2200
10/01

HOUSE BILL **1326**

AN ACT relative to the use of long-term antibiotics for the treatment of Lyme disease.

SPONSORS: Rep. Daniels, Hills 6; Rep. Vita, Straf 3

COMMITTEE: Health, Human Services and Elderly Affairs

ANALYSIS

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III. "Therapeutic purpose" means the use of antibiotics to control a patient's symptoms determined by the physician as reasonably related to Lyme disease and its sequelae.

2 Effective Date. This act shall take effect upon its passage.

Amendments

Sen. Cilley, Dist. 6
May 6, 2010
2010-1939s
10/09

Amendment to HB 1326

Amend the title of the bill by replacing it with the following:

AN ACT establishing a committee to investigate and assess access to viable and credible alternative medical practices and protocols.

Amend the bill by replacing all after the enacting clause with the following:

1 Purpose.

I. The general court recognizes and acknowledges that one of its core responsibilities is the protection of our citizens' health and well-being. One aspect of that responsibility is to ensure that our citizens have access to and freedom of choice to safe, quality healthcare alternatives to the treatment of injury and disease.

II. The history of the field of medicine is replete with examples of innovative approaches to medical care, some of which went on to dramatically change the course of medicine and benefit an untold number of lives. Some innovative approaches did not work out and some even produced deleterious effects upon patients. The determination of when to adopt new practices that have been adequately tested and scrutinized through rigorous study and research has traditionally resided, as it rightfully should, in the purview of the medical field and the relevant, recognized medical associations and regulatory boards.

III. However, history demonstrates that even in such a science-grounded field as that of medicine, entrenched traditions, politics, or other concerns, from time to time have impeded the acceptance and adoption of viable, alternative treatments in a timely manner. When such an unnecessary delay occurs, patients suffer, some through prolonged or exacerbated symptoms and some resulting in death before they have the opportunity to avail themselves of a treatment that may have offered relief.

IV. It is, therefore, with that recognition in mind that the general court finds it prudent to acquire a better understanding of the decision-making process for the adoption of new medical practices and protocols as well as how to ensure that our citizens have the freedom to choose treatment approaches that may yet to be embraced by mainstream medical practice.

2 Committee Established. There is established a committee to investigate and assess access to viable and credible alternative medical practices and protocols.

3 Membership and Compensation.

I. The members of the committee shall be as follows:

(a) Two members of the senate, one of whom shall be a member of the health and human services committee and one of whom shall be a member of the executive departments and administration committee, appointed by the president of the senate.

(b) Four members of the house of representatives, 2 of whom shall be members of the health, human services and elderly affairs committee and 2 of whom shall be members of the executive departments and administration committee, appointed by the speaker of the house of representatives.

II. Members of the committee shall receive mileage at the legislative rate when attending to the duties of the committee.

4 Duties. The committee shall:

I. Investigate ways to ensure the patients in New Hampshire have access to alternative treatment approaches that are evidence based and supported by credentialed practitioners.

II. Investigate the extent to which citizens are informed of credible alternative treatment approaches by the New Hampshire Medical Society, the state board of medicine, and the department of health and human services, as well as what may constitute a credible alternative treatment approach.

III. Determine whether medical practitioners in New Hampshire are prohibited, disciplined, sanctioned, or discouraged in substantive ways that would negatively impact their pursuit of their profession.

IV. Assess ways in which a full range of treatment approaches can be made available to our citizens while ensuring that these citizens are not put to unacceptable risks of further physical harm.

5 Chairperson; Meetings; Quorum. The members of the committee shall elect a chairperson from among the members. The first meeting of the committee shall be called by the first-named senate member. The first meeting of the committee shall be held within 45 days of the effective date of this section. All meetings of the committee shall be public meetings and fully noticed by publication by the house and senate clerks in the House Calendar and Senate Calendar, respectively. Notifications shall also be directly forwarded to the state board of medicine, the New Hampshire Medical Society, the department of health and human services, the local affiliate or member group of the International Lyme And Associated Diseases Society, and the local member representative of the Infectious Diseases Society of America. Four members of the committee shall constitute a quorum.

6 Report. The committee shall report detailing its activities, its findings, and any recommendations, including proposals for legislation to the president of the senate, the speaker of the house of representatives, the chairs of the senate and house executive departments and administration committees, the senate clerk, the house clerk, the governor, and the state library on or before November 1, 2010.

7 Board of Medicine; Disciplinary Authority. The board of medicine established under RSA 329

shall not undertake disciplinary proceedings against nor sanction credentialed medical professionals offering credible treatment approaches within their scope of practice based solely on such treatment approach. Such practitioners shall provide patients being so treated with disclosure that said treatment approach may be an alternative to mainstream medical practice, provide details as to potential adverse affects, and request a signature of acknowledgement of receipt of the disclosure.

8 Repeal. Section 7 of this act, relative to disciplinary authority of the board of medicine, is repealed.

9 Effective Date.

I. Section 8 of this act shall take effect June 30, 2011.

II. The remainder of this act shall take effect upon its passage.

2010-1939s

AMENDED ANALYSIS

This bill establishes a committee to investigate and assess access to viable and credible alternative medical practices and protocols. The bill also provides that the board of medicine shall not undertake disciplinary proceedings against medical professionals offering credible treatment approaches within their scope of practice based solely on such treatment approach.

Sen. Cilley, Dist. 6
May 6, 2010
2010-1940s
10/09

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Amend the bill by replacing all after the enacting clause with the following:

1 Purpose and Intent.

I. The general court recognizes and acknowledges that one of its core responsibilities is the protection of our citizens' health and well-being. One aspect of that responsibility is to ensure that our citizens have access to and freedom of choice to safe, quality healthcare alternatives to the treatment of injury and disease.

II. The history of the field of medicine is replete with examples of innovative approaches to medical care, some of which went on to dramatically change the course of medicine and benefit an untold number of lives. Some innovative approaches did not work out and some even produced deleterious effects upon patients. The determination of when to adopt new practices that have been adequately tested and scrutinized through rigorous study and research has traditionally resided, as it rightfully should, in the purview of the medical field and the relevant, recognized medical associations and regulatory boards.

III. However, history demonstrates that even in such a science-grounded field as that of medicine, entrenched traditions, politics, or other concerns, from time to time have impeded the acceptance and adoption of viable, alternative treatments in a timely manner. When such an unnecessary delay occurs, patients suffer, some through prolonged or exacerbated symptoms and some resulting in death before they have the opportunity to avail themselves of a treatment that may have offered relief.

IV. It is, therefore, with that recognition in mind that the general court finds it prudent to acquire a better understanding of the decision-making process for the adoption of new medical practices and protocols as well as how to ensure that our citizens have the freedom to choose treatment approaches that may yet to be embraced by mainstream medical practice.

V. It is the intent of the general court that during the duration of the work of the committee established by this act, the board of medicine established under RSA 329 refrain from undertaking disciplinary proceedings against or sanctioning credentialed medical professionals offering credible treatment approaches within their scope of practice based solely on such treatment approach, provided that practitioners provide patients being so treated with disclosure that the treatment approach may be an alternative to mainstream medical practice, provide details as to potential adverse affects, and request a signature of acknowledgement of receipt of the disclosure.

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7 Effective Date. This act shall take effect upon its passage.

2010-1940s

AMENDED ANALYSIS

This bill establishes a committee to investigate and assess access to viable and credible alternative medical practices and protocols.

Committee Minutes

Printed: 04/16/2010 at 8:56 am

SENATE CALENDAR NOTICE
EXECUTIVE DEPARTMENTS AND ADMINISTRATION

Senator Jacalyn Cilley Chairman ✓
Senator Martha Fuller Clark V Chairman ✓
Senator Betsi DeVries ✓
Senator Michael Downing ✓
Senator Sharon Carson ✓

For Use by Senate Clerk's Office ONLY
☐ Bill Status
☐ Docket
☐ Calendar
Proof: ☐ Calendar ☐ Bill Status

Start 1:05 pm recess 3:05 pm.
~~end~~ 3:18 pm end 4:55 pm
re-open

Date: April 16, 2010

HEARINGS

Monday **4/26/2010**

EXECUTIVE DEPARTMENTS AND ADMINISTRATION	LOB 206-208	1:00 PM
(Name of Committee)	(Place)	(Time)

EXECUTIVE SESSION MAY FOLLOW

Comments: *** PLEASE NOTE THE DATE, TIME AND LOCATION FOR THIS HEARING ***

1:00 PM HB1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

Sponsors:
HB1326
Rep. Gary Daniels Rep. Carol Vita

Catherine Mullen 271-3067

Sen. Jacalyn Cilley
Chairman

Executive Departments & Administration Committee

Hearing Report

TO: Members of the Senate

FROM: Patrick Murphy, *Legislative Aide*

RE: Hearing report on HB1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

HEARING DATE: April 26, 2010

MEMBERS OF THE COMMITTEE PRESENT:
Senator Cilley (Dist 6), Senator Fuller Clark (Dist 24), Senator DeVries (Dist 18), Senator Downing (Dist 22), Senator Carson (Dist 14)

MEMBERS OF THE COMMITTEE ABSENT:
None

Sponsor(s):
Rep. Daniels, Hills 6; Rep. Vita, Straf 3

What the bill does:
This bill authorizes licensed physicians to prescribe long-term antibiotics for therapeutic purposes to patients diagnosed with Lyme disease.

Supporters of the bill:
Please see the Committee file for a complete list of those who signed in to support HB 1326.
Rep. Daniels, Hills 6; Dr. Kevin Young; Dr. Donta; David Hunter, Lyme patient advocate; Greg Kettmann; Pam Veiga; Jacqueline Arlen; Marie Veselsky; Jessica Wojenski; Peter Ballou; Carl Tuttle; Julie Hall; Barbara Flaco; James Flaco; Maryland Rivera; Lauren Lamy; Amy Simoneau; Kim Schillereff; Hollis McGuire; Erin Fallon; Arlene Stoppe; Whitney Williams; Vickie Williams; Susan Patteson; Laura Herd; Doug Newton; Cheryl Ann Victor; Pamela Brown; Georgina Meser

Those in opposition to the bill:
Please see the Committee file for a complete list of those who signed in to oppose HB 1326.
Dr. Montero, DHHS; Dr. Robinson, NH Medical Society; Dr. Andelman, NH Board of Medicine; Dr. Jeffrey Parsonnet, Dartmouth-Hitchcock;

Speaking to the bill/Neutral:
Dr. Louis Rosenthall, NH Board of Medicine

Summary of testimony received:

Rep. Daniels, Hills 6

- At the House hearing on HB 1326 over 200 people attended to seek affirmation that their physicians have the right to diagnose clinically, and the assurance that their physicians have the freedom to treat their patients using the appropriate evidence based, peer reviewed guidelines that best fits the needs of those patients.
- There are currently two federally recognized standards of care for the treatment of Lyme disease, though NH's DHHS website only links to one.
- The Infectious Disease Society of America (IDSA) states that chronic Lyme disease does not exist, that treatment for Lyme disease should not exceed 2-4 weeks and that people labeled as having chronic Lyme disease do not benefit from additional courses of antibiotics.
- The International Lyme and Associated Diseases Society (ILADS) asserts that Lyme disease can be chronic and can be successfully treated with long-term antibiotics by doctors who determine the duration of treatment based on individualized clinical evaluation. The viewpoints of both standards are reflected in peer reviewed evidence-based guidelines.
- In spite of the fact that there are two recognized standards of care for treating Lyme disease, a charges political climate exists between these standards that has resulted in doctors around the country having their licenses revoked or suspended for no reason other than that they chose to treat patients with long-term antibiotics. I do not want that to happen in NH.
- It is not the intent of this bill to solve the differences between these standards, this if for the medical community to resolve.
- It is the intent of this bill to allow doctors, based on a clinical diagnosis and their professional judgment, to treat their patients according to the standard they feel best suits the need of those patients, without the fear that their license will be revoked solely because they prescribed long-term antibiotics.
- This bill does not legislate medical treatment, nor does it protect a doctor from medical board action if he or she were negligent or criminal in any way. We are simply saying that with two federally recognized standards of care for treating Lyme disease, doctors should be free to choose, based on a clinical diagnosis and their medical expertise, which standard of care best fits the need of their patients, without fear of losing their license solely because they prescribed long-term antibiotics. When NH Lyme patients are denied access to all treatment options for no reason other than their doctors are afraid of repercussions if they treat with long-term antibiotics, there is something wrong, and it not only requires, but demands legislative action to restore the patient-doctor relationship.

Dr. Kevin Young

- Family practitioner, practicing in Plymouth NH, a member of ILADS and the parent of a daughter with chronic Lyme disease. The IDSA feels that long term antibiotics for Lyme are not warranted, because chronic Lyme disease is a rare event that is extremely over diagnosed. In fact, the IDSA committee members who wrote the current national guidelines state openly in their guidelines that "late neurologic Lyme disease is a very rare event. Collectively, only one patient over the past five years was diagnosed by panel members."
- There is an alternative national guideline for the diagnosis of chronic neurologic Lyme disease. The physicians who diagnosed the people in this room follow the Burrascano guidelines endorsed by ILADS.

- This is a legislative issue because the medical community has difficulty allowing two competing guidelines. It became an issue for state government when IDSA labeled the alternative diagnosis rules as substandard care.
- Substandard care is a legal term. Medicine is always defensive. Therefore many NH physicians skip ILADS criteria and automatically use IDSA rules just to avoid legal issues. Their concern is not specifically about lawsuits. IDSA has not been able to set a precedent in the courts that ILADS criteria are substandard. In other states, however, they were successful in threatening physicians' licenses if they prescribed according to ILADS guidelines. This is having a chilling effect here in NH. The logical consequence is that patients do not have access to care if they want treatment for chronic Lyme disease.

Dr. Robinson, NH Medical Society

- This bill exempts physicians from Board of Medicine discipline for long term antibiotic therapy for Lyme disease. No physician should have a blanket exemption from Board of Medicine discipline. To date, no NH physician has been disciplined for prescribing long term antibiotics for Lyme.
- Under current lay, there is no restriction on the long term prescription of antibiotics. Today there is more awareness of the prevalence of Lyme in NH, so there is an increase in early testing. Primary care physicians take this disease very seriously and NH is fortunate to have 26 Infectious Disease specialists.
- NH licensed physicians are required to meet the standard of care for all conditions they treat. It is inappropriate to specifically legislate what is currently not the standard of care. Medical standards do change; therefore they should not be put in statute.
- It is inappropriate to select one particular disease/medical condition or one particular medication/treatment and exempt physicians from having to meet the standard of care. HB 1326 does not address insurance coverage for long term antibiotic treatment. There is no evidence-based study to show that long term antibiotic therapy is both beneficial and safe.
- In response to questions from the Committee, Dr. Robinson responded that it might be possible to publically state on the state website that they will not discipline doctors who prescribe long term antibiotics for Lyme.

Dr. Donta

- Infectious disease specialist and IDSA member. The IDSA panel never reached a decision on Lyme guidelines. The current guidelines are based on one individual's position. The guidelines are primarily based on lab testing which is not reliable. We have a diagnostic problem. We can't find the bacteria that cause Lyme. The guidelines are based on one test using two different antibiotics, and that trial didn't show any value to using antibiotics for Lyme.
- Since the guidelines were set there have been no controlled tests. We have insufficient information to know if long term antibiotic treatments will help or not.

Dr. Andelman, NH Board of Medicine

- The vote by the NH Board of Medicine to oppose HB 1326 was unanimous.
- At present, there has never been a Lyme related complaint, claim, or suit reviewed by the Board of Medicine. If one were to be filed with the Board, we would rely on appropriate consultants, whether they are in Infectious Disease, Neurology, Internal Medicine, or whatever else is necessary. We would rely heavily on their expert opinions, including consensus statements by the NIH or other appropriate national bodies.
- Thus, at this time, the Board takes no position on the clinical issues of treatment of Lyme disease, and physicians are free to prescribe appropriately. The Board would become involved only if there is a suit or complaint against a physician by a patient or family, or if there is a disciplinary action by a hospital.
- There is no precedent that the Board or its legal counsel knows of for this bill. We are unaware of any other disease, therapy, surgery, or mode of treatment which has statutory protection from oversight by the Board of Medicine.
- The Board sees this as an extremely dangerous precedent. Will other therapies or treatments be similarly exempt from Board oversight? Will the public now expect that through the legislative process it can compel physicians to practice in a certain way, either to perform or not perform a certain treatment or therapy?
- The Board is aware that there are large numbers of our citizens afflicted with a chronic illness for which there is not only no therapy, but no real diagnosis. We sympathize with those individuals who may be in constant pain, are in wheelchairs, or even bedridden, However, this is not a reason to violate out time tested system of leaving the practice of medicine to physicians, and the oversight of physicians to the Board of Medicine, with the availability of the tort system.
- In response to questions from the Committee, Dr. Andelman responded that it takes a lot to get the Board to publicly reprimand a doctor. We have to balance fairness to the doctors with the safety of the public. When research conflicts, it's very hard to punish for treatment one way or the other. If a doctor treats chronic Lyme and due to that misses another diagnosable disease two or three times the Board would come down on them. With this bill the Board would not be able to do that.
- Is willing to look at posting the Boards intentions relative to the long term treatment of Lyme with antibiotics on its website.

David Hunter, Lyme patient advocate

- HB 1326 does not legislate treatment. It only provides doctors the right to diagnose and treat clinically, as they have been taught in medical school, without fear of disciplinary action solely for treating Lyme patients with long term antibiotics.
- Many doctors in NH are reluctant to treat beyond the four week IDSA standard for fear that they might face repercussions for exceeding the four week limit. A law stating that doctors may prescribe long term antibiotics for Lyme disease without fear of disciplinary action for doing so is likely to encourage more doctors to provide effective, longer-term care for Lyme disease, something we desperately need in this state.
- This bill does not legislate care. It gives doctors the freedom to choose between the two valid, scientifically-based standards of care. Right now the NH DHHS only links to the IDSA guidelines so residents aren't even being made aware of the second standard of care. This bill will help ensure that more Lyme patients have access to all available treatment options.

Dr. Jeffrey Parsonnet, Dartmouth-Hitchcock

- We are opposed to HB 1326 because its effect would be to prevent the Board of Medicine from conducting its legally mandated role of medical practice oversight in the State. The Board of Medicine was established by the legislature because a lay body lacks the knowledge and expertise to oversee medical practice. HB 1326 would establish a dangerous precedent for other disease or procedures for which there are disagreements about guidelines for the practice of Medicine.
- Why should Lyme disease be singled out in this regard? Would the legislature similarly strip the Board of its task to oversee treatment of cancer and heart disease, allowing administration of unproven cancer treatments or performance of obsolete interventions for heart disease?
- At issue today is whether patients with long-term symptoms despite adequate treatment for Lyme stand to benefit from a prolonged course of antibiotics. As you all know, this question was put to the test in a rigorous, double-blind, randomized study, the conclusion of which is that patients who have received adequate therapy do not benefit from months or years of additional antibiotic therapy.
- HB 1326 seeks to carve out a special exception that protects physicians who prescribe certain treatments from disciplinary action by the NH Board of Medicine. In essence, the NH General Court is being asked to usurp the authority of the Board by making a medical decision on the validity of certain Lyme disease treatments. Even more troubling is the precedent is that this bill would set; passing this bill would send a message that other patient groups and doctors, who believe in the efficacy of unproven medical treatments, can count on the Legislature to allow them to practice unsafe medicine.

Greg Kettmann

- The Connecticut legislation passed unanimously and used the same language as this bill. This is only about patient choice and freedom. This bill provides doctors the freedom to treat their patients.

Dr. Montero, DHHS

- Expressed concern about setting a precedent with this bill. Lyme disease is increasing in New England and in New Hampshire specifically.
- Supports evidence based guidelines that we can have faith in. We don't have double blind test results for chronic manifestations of Lyme disease.
- The information and the tolls to know if long term antibiotics will help chronic Lyme do not exist. Studies have shown that long term antibiotics have the same success rate as long term placebos.

Pam Veiga

- Suggested the committee adopt am amendment to add nurse practitioners to this legislation.

Dr. Louis Rosenthall, NH Board of Medicine

- Stated that the Board of Medicine would respond to a complaint made by a pharmacy.

The Committee received testimony from the following people who described their experience or the experiences of a family member who has been living with chronic Lyme disease.

Jacqueline Arlen
Carl Tuttle
Maryland Rivera
Kim Schillereff
Whitney Williams
Doug Newton
Marie Veselsky
Julie Hall
Lauren Lamy
Hollis McGuire
Vickie Williams
Cheryl Ann Victor
Jessica Wojenski
Barbara Flaco
Amy Simoneau
Erin Fallon
Susan Patteson
Georgina Meser
Peter Ballou
James Flaco
Arlene Stoppe
Laura Herd
Pamela Brown

Representative Perry, Straf 3

- This bill is enabling. We don't want to legislate a standard of care. Everyone in NH is vulnerable to ticks and we should all have access to appropriate care.

Representative Chase, Hills 2

- Medical debates go on all the time. How many times have you heard, on behalf of yourself or a family member, that it is a good idea to seek a second medical opinion? How would you feel it the ability to second opinions based on evidence-based medicine, and act on those second opinions, were snuffed out for you and your family.

Representative Schmidt, Straf 4

- This isn't as dangerous a precedent as has been described.

Funding:

None

Action:

Executive action is pending.

Date: April 26, 2010
Time: 1:05 p.m.
Room: LOB 206-208

The Senate Committee on Executive Departments and Administration held a hearing on the following:

HB 1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

Members of Committee present:

Senator Cilley
Senator Fuller Clark
Senator DeVries
Senator Downing
Senator Carson

The Chair, Senator Jacalyn L. Cilley, opened the hearing on HB 1326 and invited the prime sponsor, Representative Gary Daniels, to introduce the legislation.

Senator Jacalyn L. Cilley, D. 6: We're going to open up the hearing on House Bill 1326. And I have some opening remarks first, before we get started.

I want to thank you all for coming and taking time out of your busy days to participate in the legislative process. It's my understanding that many of the attendees at this hearing have sensitivity to certain stimuli. So we have turned off the fluorescent lights, except for those small. Are those fluorescent? If they bother anybody, let me know. If there are any other, you know, conditions in the room that you have problems with, please let us know a.s.a.p. and we will do as much as we can to adjust those.

I know that many of you attended the hearing in the House, so you're familiar with the process. The Senate operates in much the same way, so there shouldn't be many surprises. Except we're under a few more time constraints that I'll talk about in a few moments.

The hearing has been scheduled for two hours, until 3 o'clock. We know that, you know, sometimes we need to be a little flexible, but please understand that all of us have a lot of other commitments on our time. I'm sure you do as well. So I'm going to ask folks to be really focused and really succinct. If we go a little after 3 that's one thing, but most of us have other commitments for the evening, so.

There are, here are the conditions that I'd like to set forward for the hearing. I will, and the members of this Committee will expect, you know, respectful conduct at all times during the hearing. I really don't want a situation where there's clapping, booing, comments that are made to people, whether they are in agreement with your views or in opposition to your views. It's just not something that we like to see happen here, and so I would ask you to honor that.

I'd also ask you to keep your testimony short and focused on key points. If you've brought written material, Cathy Mullen, sitting over here to your left, my right, is our Committee Secretary. She will be taking all written submissions of testimony, will collate that and make sure the members of the Committee have that when we meet again tomorrow.

If you have written material, I would ask that you summarize the main points for, you know, to read into, to put onto the record, but not to read your testimony in its entirety. That will slow the process down immeasurably and it will not help in the decision making with this bill. Many of us have already read a significant amount of testimony over the last week. I've read all the testimony that came before the House. I've read, you know, other material that was given to me. I have watched Under Our Skin, I have watched the DVD, part of the DVD on the floor debate. So, and I'll be giving that material to Committee members who may not have seen it all. But we have spent time already researching the bill.

If you've heard a previous speaker give testimony that captures all or much of what you are going to say, please just, please don't repeat that. Please just say that you agree with that speaker and, you know, we'll capture that on the record.

And I want to be very clear. This hearing focuses exclusively on whether we should place into statute legal protections for doctors who choose a specific course of action in the treatment of chronic Lyme disease. It's not within our powers, not should it be, to determine what course of treatment is appropriate or inappropriate. So we're not medical professionals, thus we will not be arbitrating the best medical practices in this meeting. While it's been informative to know about the many debilitating conditions that have been experienced by people suffering from chronic Lyme disease, that's not directly relevant to this hearing, and I would ask that you keep comments focused on the core question, which is why should we offer statutory protections for doctors who pursue a specific treatment approach for this disorder?

We will be calling on expert witnesses at the outset in order to help us frame the debate. And we'll do our best to move back and forth between those who are in support of the bill and those who are in opposition, although we'll provide a little bit more time for the expert witnesses. I'm going to ask them also to keep their comments brief and focused. I'm asking all others that, you know, you keep your testimony to about 2 to 3 minutes. We'd like not to be using an egg timer, although I see one in front of me. But, you know, we'll resort to that if we absolutely have to.

At times during the hearing, you may see people get up and leave. I've got a commitment at 1:30 to go to another hearing. I'll be back just as soon as I can, but there will be other people here in the room. But please don't take that personally, please don't think that, you know, it's because we don't care about this bill. It's just that we're double booked.

And then lastly, in order for the hearing to proceed more efficiently, I'll call one speaker up and I will tell you who's next on the list, so that we can have, you know, a good flow. And then very lastly, I'm going to ask the Reps, with the exception of the prime sponsor, to wait until last so that we get the public up here, because it's really their hearing. So I apologize to the Reps who may sit here for awhile, but I think that's the fair and reasonable thing to do.

So with that, let's get underway and I'd like to call the prime sponsor, Representative Gary Daniels. And following Representative Daniels, is Dr. Donta in the room yet?

Unknown: I don't think he's here yet.

Senator Jacalyn L. Cilley, D. 6: Is Dr. Young here? Okay, we'll have you next, Dr. Young.

Representative Gary Daniels: Thank you, Madam Chair. For the record, my name is Gary Daniels, I'm a Representative from Hillsborough District 6, representing the towns of Amherst and Milford. I'm also the prime sponsor of House Bill 1326 and speak today in support of the bill.

On January 28th, over 200 people filed into the House public hearing. And they came not as Democrats or Republicans, as conservatives or liberals. They came but united by one thing: that the effects of Lyme disease had directly or indirectly devastated their lives. They came seeking the affirmation that their physician was free to choose to diagnose clinically.

And also for the assurance that their physicians have the freedom to treat their patients using the appropriate evidence based peer reviewed guidelines that best fits the needs of those patients.

There are currently two federally recognized standards of care for Lyme disease. The Infectious Disease Society of America states that there's no such thing as chronic Lyme, that all Lyme is treatable within two to four weeks, and that those labeled as having chronic Lyme serve, have no benefit with that additional doses of antibiotics.

In contrast, the International Lyme and Associated Diseases Society, ILADS, asserts that chronic Lyme disease can exist and that it can be successfully treated with long term antibiotics, once it's based upon an individualized clinical evaluation. The viewpoints of both standards are peer reviewed and evidence based.

In fact, in spite of the fact that there are two recognized standards of care, a political charged environment now exists between those and has for some time. It is the not the intent of this bill to try to resolve the differences there. That's for the medical community to resolve. It is the intent of this bill to allow doctors, based upon a clinical diagnosis and their professional judgment, to treat their patients according to the standard that they feel best fits those patients, without the fear that their license will be revoked solely because they prescribed long term antibiotics.

The heart of this bill can be summed up with the answers to two questions. We are being told that there's no problem, that doctors in New Hampshire can now treat at will. However, when asked if he would fear losing his license if he treated with long term antibiotics, a doctor testifying against this legislation in the House stated that if he tested on a regular basis, then most likely someone would take notice. Who's supposed to take notice if they're actually free to treat? That question was followed, to the same doctor, if someone wasn't successfully treated in two to four weeks, where were they to go? His response: I don't know that I have an answer.

Madam Chair, members of the Committee, that's unacceptable in New Hampshire. That's unacceptable. It's unfortunate that Dr. Don MacNeil, one of the state's few Lyme experts, couldn't be with us today because he's in South Carolina. He experienced the reality of the fears voiced by the aforementioned doctor. Dr. MacNeil stated in testimony to the House that he closed his practice a few years ago, in part because of pressure from the medical community for his successful treatment of hundreds of chronically ill Lyme patients using long term antibiotics. His written testimony is the first one in the packet of written testimonies that you have received.

We have thousands of family members, friends, neighbors and constituents that are looking to us today for an answer. They have done their part by pushing aside their pain and coming to this hearing to pass this bill. This bill does not legislate medical treatment, nor does it protect the doctor from Medical Board action if he or she were negligent or criminal in any way. We're not even asking you to spend money. We're simply saying that with two recognized standards federally, that doctors should be free to choose, based upon a clinical diagnosis and their medical expertise, which standard of care best fits the needs of their patient, without the fear that they're going to be losing their license solely because they prescribe long term antibiotics.

When Lyme patients are denied access to some treatment options for no reason other than the doctors are afraid because of the repercussions that they treat with long term antibiotics, there is something wrong. And it not only requires but demands legislative action to restore that patient/doctor relationship. House Bill 1326 has the same language that passed the Connecticut Legislature unanimously on Feb. 17th of this year. This bill passed the New Hampshire House 300-56. We have the opportunity today to provide some relief to those Lyme victims who have suffered far too long without instate access to the care that they need.

And I would therefore respectfully ask that you support the passage of House Bill 1326. Thank you, Madam Chair. **See written testimony of Representative Daniels attached hereto and hereafter referred to as Attachment 1.**

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions for Representative Daniels? Seeing no questions, thank you very much.

Representative Daniels: Madam Chair, if I may, shall I read the letter from the Councilors?

Senator Jacalyn L. Cilley, D. 6: Yes, please do so.

Representative Daniels: Thank you. This letter is addressed to the Senate Executive Department and Administration, Senate hearing, regarding House Bill 1326. Dear Members of the Senate Executive Department and Administration: The Executive Council held two public hearings today that prohibited us from speaking before your Committee on the issue of antibiotic use that will give doctors the freedom to treat Lyme patients without fear of retribution. We both support the passage of House Bill 1326. With the passage of this bill, the citizens of our state will be able to work with their physicians on a treatment plan that they feel is in their best interests without fear of retribution. Sincerely, Raymond S. Burton, Executive Council for District One and Beverly A. Hollingworth, Executive Councilor, District Three. **See letter attached hereto and hereafter referred to as Attachment 2.**

Thank you, Madam Chair.

Senator Jacalyn L. Cilley, D. 6: Thank you. So we'd like to see Dr. Young next and following Dr. Young will be Dr. Robinson from the New Hampshire Medical Society.

Dr. Kevin Young: Thank you very much for this opportunity. My name is Kevin Young, I'm a family practitioner who's been practicing in Plymouth for the past 29 years.

I'm also a member of ILADS, the International Lyme and Associated Disease Society. I think that is for, due to a large part to the fact that my daughter has chronic Lyme disease. I'd like to explain why your constituents need the protection.

I assume you know some of the conflict between the two national guidelines. One being IDSA, the Infectious Disease Society of America, the other being ILADS, the International Lyme and Associated Disease Society. The conflict has to do with diagnosis, not treatment, despite the thrust of the bill. The IDSA does believe in chronic Lyme. On the other hand, they consider it a very rare event, quote collectively only one patient over the past five years was diagnosed by panel members. That is a statement in their current guidelines.

Well, what about the people in this room? I think you will find that many more than one of them feels that they do have Lyme disease. They received a Lyme diagnosis from physicians who followed the alternative guidelines. They also go with this diagnosis because no one gave them a better option and they've also continued to treat this as a chronic Lyme problem because it seems that the treatment works for them. I assume you will question them about that.

I'm not going to get into the medical issues here. I can't summarize thousands of research papers and clinical articles that went into the ILADS guidelines. They are evidence based. But this is a legislative issue because the medical community here in New Hampshire has difficulty living with two competing medical guidelines. The issue for state government is that the IDSA has presented to the medical community that the ILADS rules are substandard care. Substandard care is, in our opinion, a legal term.

Medicine is always defensive. Therefore, many New Hampshire physicians skip ILADS criteria and automatically use the alternative IDSA rules, just to avoid legal issues. The concern isn't lawsuits. I'm not aware of any precedent in the courts that ILADS criteria are substandard. The other states, however, have had successful challenges to physicians' licenses. This lesson was not lost on the physicians in this state. It has happened in adjoining states, have eventually dealt with this through legislative action. The consequence here, it's a very chilling effect on the way physicians prescribe. The patients at this point do have limited access to care if they want to treat what they consider chronic Lyme disease. That's why so many people came today.

When I am looking for specialist opinion, I send people south. I send them to Massachusetts, Connecticut, New York. It's a trip, they're willing to make it consistently, but it is a hardship and it's an insurance nightmare. Patients tell me they don't want to be restricted to out-of-state consultants, but that is the current state of affairs. There is an alternative in New Hampshire and it's something that we refer to as the specialist rounds. You go to infectious disease specialist, rheumatologist, neurologist, psychiatrist, all of whom give the same speech. I can't tell you what your problem is, go see someone else. At that point they end up back in my office. After five or ten specialists, they run out of people to ask. Ask the people here how many physicians have you seen, how many treatments have you tried before you found answers. Ask them whether their current ILADS treatments seem to be working for them.

Second quick comment about why physicians need the protection of this bill. My personal experience, my daughter had Lyme disease. She went blind, only for 15 minutes. This came back, she became unconscious repeatedly. Finally got to the point where she slept 22 hours a day, she was totally disabled. The important issue here is she was involved with multiple specialists. Turns out that after her treatment was started with antibiotics 10 years ago, the most outspoken critic of her treatment was a neurologist form Dartmouth. I had asked her to get an opinion there about a secondary diagnosis of possible seizures. The physician, whom I had known for years, said that as a courtesy to our prior relationship he would not report me for child abuse for prescribing antibiotics for my daughter. Now these were not antibiotics that I prescribed, these were prescribed by an infectious disease specialist in Boston. Now my wife was totally offended. I wasn't, I knew that this was just a result of the IDSA guidelines. But I have no question that if he were willing to challenge me about my fitness as a parent, he would be very willing to challenge my professional competence.

My daughter's better. She's graduated from high school, from graduate school. I don't think her improvement is coincidental to her antibiotics. I don't think her neurologic problems were coincidental to a confirmed case of Lyme disease. The question that I have is, how should I respond to patients who present in my office with what I believe to be chronic Lyme disease? I have the backing of national ILADS criteria and a wealth of supporting literature. Should I give my patient a choice of treatments, even if this puts me at risk, or should I refer them to the specialists whom I have used before?

Thank you very much. **See written testimony of Dr. Kevin Young attached hereto and hereafter referred to as Attachment 3.**

Senator Jacalyn L. Cilley, D. 6: Thank you, Dr. Young. I have one quick question. Could you explain the distinction, the differences in research and peer review of research between ILADS and IDSA?

Dr. Young: The difficulty with determining who has an infection is due to the fact the germ has an amazing ability to hide. If it can hide from the patient's immune system, it can hide from our testing. Therefore, testing is not entirely reliable. The results are always statistical. Since we're also talking about an infection of the brain where biopsies are not an appropriate way of investigating, there is no proof that is accepted by IDSA that people with this syndrome have active infection. Their comment is they've had, Lyme infection, in the past but their current neurologic syndrome is not related, it's coincidental.

Senator Jacalyn L. Cilley, D. 6: Okay. Are there other questions? Senator Fuller Clark.

Senator Martha Fuller Clark, D. 24: Thank you very much. Could you just enlighten us as to how this very difficult issue has been handled in other states?

Dr. Young: I'm not sure I'm the person to answer that question. I know that Connecticut and Rhode Island have passed bills protecting physicians for prescribing. That California has as well, they have a biomedical research industry and that was felt important there, I understand. That Virginia and Pennsylvania are considering these, this law at this time. There have been other Lyme related laws in other states, but perhaps some of the other people would know better.

Senator Jacalyn L. Cilley, D. 6: Follow up.

Senator Martha Fuller Clark, D. 24: Yes. Could you also comment on the fact that you're inviting the Legislature, in a sense, to enter into the realm of what is medical, appropriate medical practice and what isn't?

Dr. Young: I am asking the Legislature to address the fact that medicine is defensive and we do need the protection of the Legislative to allow us to use national guidelines. This is nothing I've ever run across before in other medical issues, but it's very much the case and now that New Hampshire is the number one per capita for incidence of Lyme disease, this is an issue for us.

Senator Jacalyn L. Cilley, D. 6: Follow up.

Senator Martha Fuller Clark, D. 24: Just one question, which is that you're saying that there's no other conflicting treatment within the medical community that has to be, that requires legislative protection? Obviously the concern here is that we do this for one type of treatment. Then how do we know that even though you're using national guidelines, are there not other aspects of the practice of medicine where there are conflicting national guidelines or will you be asked to do the same thing?

Dr. Young: There are conflicting guidelines, that is part of my industry. On the other hand, it's very unusual for one group to label the other as substandard care. That's the only case I know of.

Senator Jacalyn L. Cilley, D. 6: Thank you. Senator DeVries.

Senator Betsi DeVries, D. 18: Thank you, Madam Chair. And certainly, Senator Fuller Clark went down the road of some of the information I'm hoping we can glean from you. When one group has the ability to say that another group's treatment plan is substandard, that is, this is the only time that you have seen that sort of outcome?

Dr. Young: Yes.

Senator Betsi DeVries, D. 18: And how is, we've looked at how we're dealing with this in other states. Are there other countries that are kind of looking at the same scenario that we have before us today?

Dr. Young: I'm not aware of the politics in other countries. I know that Lyme disease has different strains. And the European strain is different. In fact, there are 23 strains. That therefore IDSA does not consider international literature particularly applicable to treatment guidelines in the United States. The ILADS group does base their guidelines on international medical literature. But I don't know the politics.

Senator Jacalyn L. Cilley, D. 6: Okay, follow up.

Senator Betsi DeVries, D. 18: Follow up, thank you, Madam Chair. Can you help us understand why the Infectious Disease has more clout, if you will, over the ILADS treatment plan?

Dr. Young: They're the professional organization of the people that we rely on to advise us about infectious disease. They are very connected with the international, national body is very connected with their group of specialists. ILADS is a, both a grassroots and a research and an industry approach that really has not marketed itself in any way or intruded. It's kept a low profile and that is a political problem.

Senator Betsi DeVries, D. 18: Can I ask an additional question, Madam Chair?

Senator Jacalyn L. Cilley, D. 6: Follow up.

Senator Betsi DeVries, D. 18: I think many of us, if not all of us, have heard about some of the cons that can develop if you continue to use antibiotics for, you know, supervise and that sort of thing. And I haven't heard anything in testimony yet. But has this been part of the resistance to the long term antibiotic use? Is there anything down, resistant organisms that we ...?

Dr. Young: Of course. The resistance is not the specific indicator. It's that the antibiotics used for long term Lyme are toxic. There is a risk benefit decision. These are standard decisions that physicians feel comfortable making with their patients. The controversy here is diagnostic. If there is such a thing as chronic Lyme, then these antibiotics are indicated. The argument has to do over who has the disease.

I should add that there are studies that refer to the toxicity of Lyme treatments and in fact, the toxicity is extremely low in the published study that I know specifically on this issue. The only death was someone who died of their underlying Lyme disease.

Senator Martha Fuller Clark, D. 24: Follow up.

Senator Betsi DeVries, D. 18: Thank you, Madam Chair, the new Chair. So if we, you spoke earlier about how ILADS treatment plan is a result of evidence based research. Was the overlaying issue of developing more resistant organisms part of the consideration of the treatment plan? Or is that just kind of an adjunct study?

Dr. Young: It is not the primary thrust. It is definitely true that overuse of antibiotics is a national issue. Antibiotic resistance is a national issue. But the antibiotics typically used for Lyme disease are not ones that have high rates of resistance but, yes, I would consider that a concern and I always counsel my patients that they're using antibiotics that do potentially lead to resistance.

Senator Betsi DeVries, D. 18: Okay, thank you.

Senator Martha Fuller Clark, D. 24: Are there questions from anyone else on the Committee at this time? Thank you. I'd now like to call upon Dr. Robinson.

Dr. John Robinson: Thank you, Madam Vice Chair and members of the Committee.

Senator Martha Fuller Clark, D. 24: Thank you.

Dr. Robinson: My name is Dr. John Robinson, I'm a neurologist by training. I practiced in Portsmouth for a number of years, encountered some patients with Lyme disease. Am currently a medical director of Schaller Anderson, on contract with the State Medicaid Program to provide care coordination and management for folks. And I am President of the Medical Society for this year. And I'm here to speak in opposition to the bill.

I've provided samples of my testimony and I'd like to highlight a couple of those points. I would defer to other clinicians that will testify later to speak more to the clinical issues. I would say, however, that physicians in general in the state of New Hampshire are very much aware of the condition of Lyme disease, very attuned to it, diagnose it or attempt to diagnose it very often. We're also fortunate in the state of New Hampshire to have 26 infectious disease specialists available to help manage the condition of Lyme disease.

I would point out to you that at this time, no physician in the state of New Hampshire has ever been disciplined for prescribing antibiotics long term for Lyme disease, and under current law there is no restriction on such a practice. It is our contention that because of that situation, the bill is not necessary and, in fact, treads into dangerous territory. As comments and questions have alluded to, it begins to address specific practices of medicine and specific standards of care for medicine or lack of standard of care. It's our contention that those issues are more rightfully the province of the Board of Medicine and, for that matter, the medical liability arena. Standards of care, we believe, should not be legislated. Medicine, as I think people are very much aware, is a very fluid dynamic and ever changing and evolving

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profession. And to put one particular exemption from a particular medical practice into legislation risks having to undo that legislation should the controversy ever get resolved clinically to determine that long term antibiotic therapy is not clinically appropriate. We would then have to change the legislation. So we are in agreement with that line of reasoning.

We feel that no one particular disease or medical condition or one medication or treatment should ever be put in legislation and specifically should exempt any physician from review of that standard of care. I'd be happy to entertain any questions. **See written testimony on behalf of the New Hampshire Medical Society attached hereto and hereafter referred to as Attachment 4.**

Senator Martha Fuller Clark, D. 24: Are there questions for Dr. Robinson? I do have a question. Which is, is there no way given what's happened in a number of other states, that the Board of Medicine could not issue a statement that they will not discipline physicians in New Hampshire with regard to how they choose to treat Lyme disease at this time? Because obviously the concern that we're hearing is that there are certain physicians who won't treat long term Lyme disease in the state because they're concerned about what's happened elsewhere. If you could comment on that.

Dr. Robinson: I agree that that is a possibility. It certainly would be a feasible way of addressing it, but I would really defer to Dr. Andelman, who is due to testify a little bit later this afternoon to address that.

Senator Martha Fuller Clark, D. 24: Okay, great. Thank you. Other questions? Thank you very much. Next, I'd like to call upon Dr. Samuel Donta. Welcome. And just let me say after that, I will be calling upon Dr. Andelman. Welcome.

Dr. Samuel Donta: Thank you.

Senator Martha Fuller Clark, D. 24: For the record, if you could state your name.

Dr. Donta: Yes, my name is Dr. Sam Donta, D-o-n-t-a.

Senator Martha Fuller Clark, D. 24: And you reside where?

Dr. Donta: And I reside in Falmouth on Cape Cod.

Senator Martha Fuller Clark, D. 24: Thank you. If you'd like to proceed with your testimony, we'd be delighted.

Dr. Donta: That's fine. I'm here on behalf of the people of New Hampshire that I've been seeing over the last 15 to 20 years while at Boston University Medical Center. And since I retired from there in 2003, continued to practice in Boston until this past November. And continue to practice on Cape Cod. I'm an infectious disease person. I was in academic medicine for 30 some years, head of Infectious Diseases at the University of Iowa for 11 years. Eleven years at the University of Connecticut, and then Professor of Medicine for 10 years before I retired from Boston University.

It was in Connecticut that I became aware of the problem of Lyme disease. And when I first opened a clinic there, it became obvious that the criteria for the diagnosis and treatment for Lyme disease were limited. And unfortunately, they're still limited today. And I belong to the Infectious Disease Society of America. I was on the original guidelines panel. That panel never reached a decision in our discussions about chronic Lyme disease. I was one of the authors of the section on chronic Lyme disease.

Because the Infectious Disease Society wanted to proceed with some kind of guidelines, the committee chairman at the time was asked to step aside, that was Dr. Luft. And a new chairman was appointed so that they could expedite the creation of the guidelines. That person and a couple of the other people created the guidelines, did not take my section into account and basically, based on his opinion, said this is what we know or don't know about chronic Lyme disease. Basically, we don't think it exists. And based on that guideline and subsequent.... And I could not sign that document, I was told there would be no minority report. And I think based on that, the Attorney General of Connecticut when the 2006 guidelines came about. And by the way, I asked to be on that committee, was told no, my opinions were not in concert with the other people. So I was not permitted to be on that committee to offer my opinions, which are based on science and experience over a long period of time.

The two problems we have is that the diagnosis is based primarily on the laboratory testing, which is inadequate. We really don't use antibody testing as a way to tell if people have or do not have a disease. You can say they've been exposed to the disease, but once you have it. If you have Hepatitis B, Hepatitis C, if you have antibodies against whatever, that no longer allows you to say whether you still have it or not. Sometimes there are some tweaks in the laboratory test to help us, but we don't have a viral load equivalent to Hepatitis B or C or AIDS. So we have a diagnostic problem, and I think that was one of the issues with the guidelines. And I think they wanted to make it easy for doctors. You have a test that's positive, you have a test that's negative. But we cannot find the bacteria even in the test that's positive with the big swollen joint, a patient has strongly positive test results. So it's not like you have a sore throat, you want to find out if it's strep, you can take a culture or find the antigen.

So we have a diagnostic problem. You can't say you have Lyme disease when the test is positive and if the test is now negative or the test was never positive, you no longer have Lyme disease because you've treated it. Because then that isn't logical.

So the second part, that rolls over into the treatment. And the treatment guidelines are based on very limited data, on one trial which used IV Seftriaxone, an antibiotic, for a month followed by two months of oral doxycycline. And based on the failure to see some obvious progress as judged by criteria which are not the easiest criteria. Having done Gulf War Veterans research myself, when you get into the chronic fatigue type of scenario, what markers do you have of whether you're making progress? You basically ask the patient, how are you compared to what you were a month or two before? Or three months before? So, okay, that's the best we have.

The problem then became, because that trial didn't show any benefit on the people who received the treatment versus the placebo, it was concluded that antibiotic treatment was of no value. Well, if you did one trial on cancer and it failed, would you stop at that point and say that no further treatment was necessary? Well, I analyzed that information and I wrote a letter to a New England Journal article in response, saying that one month of IV Seftriaxone does not make three months. And IV Seftriaxone probably is not, even though there are some people who have improved. It turns out that it's probably not working as an antibiotic, it's an anti-neurotoxic agent. We still don't know. And the two months of doxycyline, I could have told them ahead of time doesn't work. Tetracycline, a different antibiotic in the same family, appears to work.

There have been really no controlled treatment trials since. We tried to, while I was still at Boston University, to have grants approved and they were not approved because there was no money to fund them. So the field is stagnant from that point of view and I think it's inappropriate for any guideline to be imposed upon physicians when we don't have enough information. And I think that's the problem that we have here. We have it in Massachusetts as well, where legislation is kind of not sure where it's proceeding at this point.

So my recommendation is that the Legislature... Unfortunately, I think, as much as you might not want to mandate medical practice, I think physicians have been put into a situation where they're going to be blocked from having any interest in these patients who suffer from varying degrees. They might have a milder form of Lyme disease and that's not a big issue. But the ones that have a more moderate or severe is where the problem is, and I think physicians right now.... We're not, people who have the scientific know how like myself, are not stepping up to analyze the problem and it's being left to people to come up with sometimes over the top recommendations. Not to be critical of naturopathic or allopathic regimens, but we don't have a concerted effort. And I've tried to get our Society to address this and it hasn't chosen to do so.

And these revised guidelines, and you may hear from somebody who's on the review panel for that, are inadequate as well. They really punt, or instead of punting, they're staying dogmatic that these current guidelines are based on the best available science and that tells us that chronic antibiotic treatment isn't available, isn't worthy or effective. Well, that's not correct. It's insufficient information and even though my published studies show that tetracycline and one of the other antibiotics works very well, I acknowledge these are observations and are not controlled treatment studies. Nonetheless, that's a first step towards saying that they work. And we've had, fortunately, hundreds of patients from New Hampshire, I don't know if it's thousands, that myself and one or two practitioners in New Hampshire have had the pleasure of seeing them improve on these treatment regimens.

Thank you.

Senator Martha Fuller Clark, D. 24: Thank you. Are there questions for Dr. Donta? I do have one question for you. Could you tell me what is the situation in Massachusetts? Have you seen physicians in Massachusetts who have chosen to choose the chronic antibiotic long term treatment disciplined or lost their license through the Board of Massachusetts (sic) in Massachusetts?

Dr. Donta: There have been two recent ones that decided to stop practicing treating Lyme disease patients, because they didn't want to for fear that they would be disciplined. We have talked with the Board of Registration in Medicine and Massachusetts' view is, from the best I could talk, see from the representative, the lawyer, they have no predetermined opinion about this. They would take it on a case by case basis. So I don't know anyone who's been disciplined.

Certainly there have been criticisms of some of the people who have created some of the guidelines. But you can't find fault technically, scientifically with those people because it's their opinion. And right now, we're in the opinion stage without anybody saying what's right or what's wrong. So I think people are still blocked. They're not interested, I'm going to have a hard time interesting anybody to really get into this because they don't want to bother with this, they're busy enough with other issues, is my response.

Senator Martha Fuller Clark, D. 24: Thank you. Yes, Senator DeVries.

Senator Betsi DeVries, D. 18: Thank you, Madam Chair. Has the veterinary field, which also with dogs obviously dealing with Lyme disease as well and showing positive Titers. Are they part of the evidence based treatment that points to, because I would assume there's greater flexibility in experimentation with the dogs? Are you familiar with any shift that has occurred within the veterinarian field?

Dr. Donta: Veterinarians are always, I think, the first ones to be aware of a problem. I mean, when Vermont or New Hampshire or Maine said that no, we don't have Lyme disease, it was the veterinarians were the first ones that, well, our dogs have Lyme disease so these ticks must be here. But I'm not aware of any particular movement or... I don't have the answer for you.

Senator Betsi DeVries, D. 18: Thank you.

Senator Jacalyn L. Cilley, D. 6: Are there any other questions? Thank you, Dr. Donta.

Dr. Donta: Thank you.

Senator Jacalyn L. Cilley, D. 6: Okay, so Dr. Andelman is next and following him, I'd like to hear from David Hunter.

Dr. Robert Andelman: Good afternoon. For the record, I'm Dr. Robert Andelman, I'm President of the Board of Medicine. And I'm here basically with the authorization of the Board of Medicine to oppose HB 1326.

The first thing I want to say is that the Board met in March and April and voted unanimously to authorize me to work to oppose this. The individuals on the Board of Medicine I've left for you with my material. Basically, at this point there are six physicians, one physician's assistant and three public members. That's a pretty broad group in terms of experience. Our vote was unanimous in terms of this bill.

Second, I'd like to say that there's not now a case in front of the Board of Medicine regarding Lyme disease and I've polled the administrator and the Board investigator, who go back 23 years. And no one can remember a case before the Board involving Lyme disease, whether it was acute or chronic or anything else.

So, if, the Board investigates patient and family complaints. We investigate all lawsuits and claims and we investigate all insurance reserves that are set aside for any, even a potential suit. And at this point, we really take no position, you know, on the whole Lyme debate. I'm an anesthesiologist, this is not my area. I know literally nothing about this area clinically. But if the Board got such a case, it would be, you know, we decide on an individual basis. We would send this out to expert reviewers in one or more fields, whether those reviewers were in I.D. or neurology or internal medicine or whatever. And we'd put it together and make our best decision.

So basically, I mean after the testimony that I've already heard, I'd like to say that if there is a legitimate argument in the literature and there's no consensus, we are loathe to come down on a physician. I'll give you a perfect example, not Lyme, but another area. We had a physician who operated on a patient. After surgery, the patient developed a pulmonary embolus and died. And obviously there was a lawsuit resultant, and the allegation was that the physician didn't take proper precautions in terms of anticoagulation to prevent the pulmonary embolus. And bottom line is, the physician presented information to us that there was conflict and lack of agreement in the literature about, you know, the best approach. And when we got that information, we did not take any action whatsoever. And I think that all of us on the Board are, we try to be reasonable, we try to make decisions with, keeping in mind that there but for the Grace of God go I. And we're loathe to, you know, reprimand or publicly discipline anyone when there is a lack of consensus in the literature. At the most, we send a confidential letter of concern saying, you know, this looks like it might be a problem, you need to watch your practice.

Third, I'd like to tell you. We have, we see no precedent in the law for a bill of this kind. We're unaware of any other treatment or a surgery or procedure or therapeutic modality that has statutory protection from oversight of the Board.

Fourth, obviously we see this as an extremely dangerous precedent. In the future, the door's open. You know, what other treatments or therapies or procedures will also enjoy statutory protection from oversight by the Board of Medicine? Will the public expect that it can go to the Legislature and get protection for some type of treatment that it wants or doesn't want? Examples are vaccinations, radiation from CT, the numbers of, the number of controversies go into the dozens. And we're afraid that the door will be open and this will be bad.

Bottom line here is who decides medical practice? Who decides standards? Is it physicians or is it the Legislature? And our position is that traditionally in New Hampshire our time worn, our time proven practice is to leave the practice of medicine to physicians and to leave oversight of medicine to the Board of Medicine. And also to the tort system, because remember patients' families, estates, can go to the tort system.

Now I've talked with all the Board members about this and we're acutely aware that there are large numbers of patients, of our citizens in this state who have chronic diseases of one sort or another. And we're aware that these people may live in constant pain, may be in wheelchairs, may be bedridden. And there may be no good answer as to what they have, no real diagnosis, let alone a therapy. We feel that this bill does not address that. We feel it's a bad precedent and we feel that the practice of medicine, the standards of medicine should be left up to the literature, to clinical and research trials, to consensus conferences. And basically the practice of medicine should be left up to physicians and not the Legislature.

Thank you. **See written testimony of Dr. Robert Andelman attached hereto and hereafter referred to as Attachment 5.**

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions for Dr. Andelman? Senator DeVries.

Senator Betsi DeVries, D. 18: Thank you. Thank you, Doctor, for bringing your testimony. I guess the confusion I have is why some of that evidence based medicine might be lagging so many years? Because Lyme disease and its effects just don't seem to be that new. We've been watching it progress up the East Coast into the northernmost states, starting in the Carolinas, I believe, some decades ago. So why is it taking so long to get that kind of evidence based outcomes?

Dr. Andelman: I'm sorry, I can't answer that. I'm not a specialist in ID.

Senator Jacalyn L. Cilley, D. 6: Follow up, Senator DeVries.

Senator Betsi DeVries, D. 18: An additional question if I might. Because I did hear you say that there wouldn't be, though it may be a stretch to use the word a censure, as you would, that you would review a case if it was brought to your attention as a Board. Why would a physician trying to treat patients with long term antibiotics feel that the outcome in New Hampshire would be any different than it might have been in Massachusetts or Connecticut or some of the other examples that we have heard, where licensing has been threatened?

<u>Dr. Andelman</u>: Boards of Medicine are very different state to state. I will tell you that we get reciprocal action cases from other states and we've seen a number of things from Florida that, quite honestly, looked so trivial we've ignored them.

Most, I think most public actions involve an egregious problem. It takes a lot to get to public discipline, meaning a reprimand or fine or requirement for medical education, CME or something like that, continuing medical education. And it takes an enormous amount really for someone to lose his license, even for a month or two. And I can't say, states are very different. You know, we constantly are balancing the safety of the public with fairness to physicians. And if there is a controversy in the literature, we are hesitant to come down hard on a physician who is doing his best to take care of his patients.

<u>Senator Jacalyn L. Cilley, D. 6</u>: Follow up.

<u>Senator Betsi DeVries, D. 18</u>: Follow up question if I might. Because I did hear you offer testimony that if a practice was found to be doing something that there wasn't clear consensus about, there was that disagreement in the medical community, that you may be advising them that they should change some thing in their practice. Would you continue to advise if it came to your attention a second time or a repeated offense, if you would.

<u>Dr. Andelman</u>: It depends on the situation. If the case that came to our attention was a complaint that someone's treating chronic Lyme disease with chronic antibiotics and there's a true lack of consensus in the literature, it's unlikely we're going to do anything. That's conjecture, okay? If there's a lawsuit that someone treated chronic Lyme disease for two years with chronic antibiotics and missed an otherwise discoverable illness that now became permanent or caused injury or death, that's a totally different situation. Anyone, any physician can make a mistake. If that physician was acting in good faith in treating chronic Lyme disease and missed a diagnosis, that's not necessarily something we would come down on unless it were egregious. If that same thing happened a second or third time, we would come down on that physician.

<u>Senator Jacalyn L. Cilley, D. 6</u>: I'm going to jump in here for just a moment. I know Senator Downing has a question and then Senator Fuller Clark. But you just went to the heart of one of the concerns that I have about the way the bill is written right now. And that is, if that second

situation occurred that you just described, where a physician is treating chronic Lyme with long term antibiotic use and there is reason to believe, something goes vastly awry and there was another underlying condition that might have contra-indicated or whatever. Is it the Board's opinion that this bill would preclude sanctioning that physician in any way with this legislation?

Dr. Andelman: Absolutely. Because I've looked at the bill, with and without the amendment. The language leaves too much wiggle room. Basically, as long as the physician treats pursuant to a clinical diagnosis based on knowledge obtained through the history and physical exam, he's immune and protected, no matter what he missed. This is a dangerous ...

Senator Jacalyn L. Cilley, D. 6: That's one of the things I'm having checked by the attorneys.

Dr. Andelman: A dangerous bill for that reason.

Senator Jacalyn L. Cilley, D. 6: Okay. Senator Downing.

Senator Michael W. Downing, D. 22: Thank you, Madam Chairman. Dr. Andelman, I know it's not your field of expertise, but you're the President of the Board of Medicine. Can you tell me exactly what is preventing physicians from practicing this course of treatment now?

Dr. Andelman: No, I cannot. It's certainly not the Board of Medicine. We have not only no cases, but we have nothing on our website about, you know, treatment of Lyme disease. We've taken no stand, there's no policy. We have policies on treatment of chronic pain with long term prescriptive narcotics. We have, you know, policies on a number of difficult and hot issues, but nothing on Lyme. So I do not know how to answer your question.

Senator Jacalyn L. Cilley, D. 6: Follow up.

Senator Michael W. Downing, D. 22: Thank you. There's nothing in your rules or the statutes that would pertain to prohibiting a physician from prescribing this course of treatment for Lyme disease?

Dr. Andelman: No, there is not.

Senator Michael W. Downing, D. 22: Thank you.

Senator Jacalyn L. Cilley, D. 6: Senator Fuller Clark.

Senator Martha Fuller Clark, D. 24: Yes, thank you so very much. I wanted to ask you, since you have some other policies on your website, if it would not be possible to put a policy that would relate to Lyme disease on your website that would simply address this issue. That as long as there is controversy, or let's say conflicting opinions about the best treatment for long term Lyme disease, there's no intention on behalf of the Board of Medicine to investigate such situations. However, you would always reserve the right to be able to investigate a physician for other types of practices or issues. Given that this is such a controversy, given that we've heard that there are physicians in New Hampshire that seem to be concerned about, you know, wanting to use this as a preferred treatment but feeling that they could lose their license.

That's one question, and the second question is, could you tell me how many physicians on an annual basis actually lose their right to practice?

And I guess the third part of this would be what, if you know, what sort of drove, for instance, the example that's being given to us over and over again is Connecticut. What sort of drove them to start disciplining doctors in Connecticut and taking away their licenses around this issue?

Dr. Andelman: Okay, complex three questions.

Senator Martha Fuller Clark, D. 24: Sorry.

Dr. Andelman: First off, number one, the Board has no intention to act relating to Lyme at this point.

Senator Martha Fuller Clark, D. 24: So is it possible to put that on your website?

Dr. Andelman: It is, actually. We have a, prescriptive drug abuse and treatment of chronic pain is a huge issue, you know that. We have a very nice policy on the website relating to the proper treatment of chronic pain with narcotics. Narcotics is what it boils down to. And that's on our website, it basically involves proper care of knowing the patient, following the patient, making sure the patient isn't abusing the drugs, etc., etc. We don't want pill mills in New Hampshire. That's a perfect example.

The question is, can we translate that model into something relevant to the treatment of chronic Lyme? And of course I have no idea. I think we'd be willing to tackle it. I certainly would be willing to tackle it and try to come up with something. I'd be willing to work with all parties involved. Although my specialty is anesthesia, obviously very far from this stuff.

Senator Martha Fuller Clark, D. 24: Sure.

Dr. Andelman: I can, you know, spearhead and lead that. And actually, that sounds quite challenging to me. I would enjoy that. So it's possible that we could put together something like and I think ...

Senator Martha Fuller Clark, D. 24: I'd like to ... Follow up.

Dr. Andelman: ...my guess is the Board would be eager to tackle that.

Senator Jacalyn L. Cilley, D. 6: I think this is something we could do in executive session.

Senator Martha Fuller Clark, D. 24: Okay. I'd just like to say that I think that would be the preferred way to go, to try to find some middle ground in this difficult situation.

Dr. Andelman: I agree. And speaking for myself, I'd be willing to tackle that.

Senator Martha Fuller Clark, D. 24: Thank you.

Senator Jacalyn L. Cilley, D. 6: Are there additional questions for Dr. Andelman? With that, thank you very much, Dr. Andelman. I'd like to call Dr. Parsonnet up next, with Greg, no, I think I got off track here. No, it's David Hunter, and then Dr. Parsonnet next. And I'm going to ask even our expert witnesses to try to keep the, you know, your testimony even shorter. It's clear that the Committee has a number of questions for each witness, and at the rate we're going.... We have 44 speakers, we are only on number 6. So I am going to ask to start speeding this up, please. With no disrespect to anybody testifying, but we've got to get it done. Mr. Hunter, welcome.

Mr. David Hunter: Good afternoon. My name's David Hunter. I've been involved with Lyme disease as a Lyme patient advocate for the past 10 years. I currently am the facilitator for the Greater Manchester Lyme Disease Support Group and also the co-Chairman of the Bedford Lyme Disease Council.

Amazingly, some 30 plus years after Lyme disease was first discovered ...

Senator Jacalyn L. Cilley, D. 6: Mr. Hunter? Forgive me for stopping you. I'd ask that you not read your testimony but give it to Ms. Mullen and we could just summarize the main points.

Mr. Hunter: I'll try to do that.

Senator Jacalyn L. Cilley, D. 6: Thanks.

Mr. Hunter: It's hard. A lot of this, you guys are going to miss nuances. This is a very complex subject.

Senator Jacalyn L. Cilley, D. 6: Oh, I know. I've been reading it for days now.

Mr. Hunter: But even there, believe me, 10 years and there's still a lot.

Senator Jacalyn L. Cilley, D. 6: Okay.

Mr. Hunter: But I will try to summarize. You've heard today that the disagreement is primarily over the difference between the IDSA's view that Lyme disease stops at the acute form. There's only four weeks of antibiotics and you no longer have the bacteria in your system. ILADS obviously disagrees and says that there is a chronic Lyme, that the bacteria can persist beyond four weeks. And I can tell you through 10 years of doing patient advocacy, it's been amazing to see how many patients have benefitted from long term antibiotic use. It's not a question mark from the standpoint of advocates or patients. There is zero question in terms of whether antibiotics have saved lives and restored quality of life to people.

House Bill 1326 does not legislate treatment. That's really important. We keep hearing that the legislators are asked to legislate treatment. If you read the bill, what we have in this bill, it provides doctors the right to diagnose and treat clinically as they have been taught in medical school, without fear of disciplinary action solely for the, without fear of disciplinary action solely for treating Lyme disease with long term antibiotics. It doesn't carve out an exemption where you can't go after Lyme doctors for doing things inappropriately. It does not preclude some of the things that the previous speaker talked about. All it's saying is that, just for prescribing long term antibiotics, a doctor should not be subject to disciplinary action.

We keep hearing that we shouldn't be carving out an exemption. Well, the real exception is Lyme disease is carved out as an exception. It's getting treatment that no other disease gets out there. We are seeing that a second standard of care is not allowed in many cases. For all practical purposes, 99 percent of the medical community will not treat beyond four weeks because of the one set of guidelines. Now there's a second set of guidelines. If you go to most of the doctors, you're not going to hear that there's a second set of guidelines. The American Medical Association says that patients are supposed to be told about alternative treatments. That you're supposed to be given your various options and told the risks and benefits to those options. And then the patient is supposed to have a say in how treatment goes forward. With most diseases, that happens. With cancer that happens. With back ailments that happens. With heart disease that happens. With Lyme disease, that doesn't happen in 99 percent of the cases. I mean, I don't know how much clearer that can be made. We are looking at a situation where patients are being sent home without any answers because most of the doctors are following one set of guidelines and don't even know the other one exists or at least believe it's not a viable set of guidelines.

The, you know, if you look at the New Hampshire Department of Health and Human Services. They only have the IDSA guidelines on their website. There's no mention of a second set of guidelines. These are guidelines that are being used across the world. These are guidelines that have been used for decades, and yet they're not even listed. And we wonder why we're here and asking you guys to take a part in this?

The IDSA opposes this bill and would like you to believe they're the final authority on Lyme disease. They convey the belief that Lyme disease is an easily diagnosed, easily treated disease and generally it can persist, it cannot persist after four weeks of antibiotics. If properly diagnosed and treated in its early stage, that's true. It's generally an easy disease to treat. If not caught early, if not diagnosed or treated early, it becomes a far different disease and affects patients both physically and neurologically in very, very profound ways.

We know, this is where the idea of saying ILADS are a very different fundamental viewpoints. I mean, let's think about that. The IDSA, in this day and age, the IDSA is denying the existence of chronic Lyme disease. Most people live in this state know there's chronic Lyme disease, know people who have suffered tremendously with it. And yet we're still in that part of the debate.

There's plenty of science still to be discovered in terms of Lyme disease. But it certainly shouldn't be over whether a bacteria can persist beyond four weeks of treatment. The IDSA would have you believe that all scientific evidence is on their side. They like to contend that they practice evidence based medicine, implying that ILADS doesn't. This is nonsense. You know, these booklets are the 1,300, or more than 1,300 pages of research that was used in the presentations on July 30th at the IDSA guideline review panel, or panel review last summer. This is ILADS science. The idea that somehow they're coming up with their ideas just from anecdotal evidence is silly. There's plenty of peer reviewed science out there. There's also science that is, where there's room for debate. But it's not fair to make it sound like one side has all the weight of the evidence and the other side is just kind of there, coming up with these hopes and dreams.

You know, we know that Borellia burgdorferi, the spirochetal bacteria that causes Lyme disease, is a cousin of syphilis, another spirochetal disease. We have known for decades and decades that syphilis can survive weeks and months of antibiotic treatment. So where's the leap of faith we have to make to understand that Borellia burgdorferi can also survive four weeks of antibiotics? I mean, again, some of these people need to step back and say, you know, just because one organization has tremendous clout and authority out there, is that any reason to close our eyes to what seems pretty obvious.

The IDSA states that persistence of that bacteria beyond four weeks is microbiologically implausible. Look at the syphilis model, just that alone. And there's plenty of other evidence to say, that's a huge statement.

Senator Jacalyn L. Cilley, D. 6: Mr. Hunt, I apologize again, but I've explained that's it, this is not what's before us, to referee between two groups or to determine what the best practice is.

Mr. Hunter: Let me ...

Senator Jacalyn L. Cilley, D. 6: Only to the bill.

Mr. Hunter: Let me stipulate, this is not about asking you guys to referee between two organizations or come up with the answers on this, but you need to understand the politics of it and the debate to get to where you have to get. By all means, the last thing we want is a legislature determining this debate. This debate has not come even close to an outcome in 30 plus years of scientists on both sides. So how in the world are you supposed to do that? We don't want you to do that.

And again, I go back to the bill. The bill is not about, and people misstate this many times. It's not about legislating one standard of care over the other. We are the first ones to say there are two standards of care. What this is about is doctors' choice, freedom of choice, patients' freedom of choice. And we need this bill because without it, the doctors and many doctors are there because they only know one standard or they believe in one standard. But there are several doctors, I've been in touch with many and I hear from patients who say their doctor says to them, there are doctors out there who say they're intimidated. They know that 99 percent of the political argument is on one side. Not the scientific argument, but the political argument. That most of the medical establishment believes one side. They

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get peer pressure. They have seen in other states where this has become a very, you know, your license is in jeopardy if you do this. So it is a situation where doctors in this state, although there's no precedent. The Medical Board is right. They have not gone after any doctor. There's no evidence that they've even thought about doing that. But we are seeing it in states right around us. We are seeing the IDSA get very aggressive in trying to promote this idea that the ILADS should be shut down, that their viewpoint should not be accepted as anything legitimate. And that is the issue. **See written testimony of David Hunter attached hereto and hereafter referred to as Attachment 6.**

Senator Jacalyn L. Cilley, D. 6: And that is in the testimony in the House. Are there questions for Mr. Hunter? Seeing none, thank you very much. I'd like to call Dr. Parsonnet. And then following him, Greg Kettmann. I would ask you again, please be brief. And we will open it up to questions.

Dr. Jeffrey Parsonnet: Thank you. My name is Jeff Parsonnet. I'm a member of the Infectious Disease Section at Dartmouth Hitchcock. I'm also a Professor of Medicine at Dartmouth Medical School. I'm a fellow in the IDSA, Infectious Disease Society of America, and also a member and a past President of the Northern New England Infectious Disease Society.

And I recently served on IDSA's Lyme Disease Guideline Review Committee, which was established in response to the anti-trust investigation by the Attorney General of the State of Connecticut. Most importantly, though, I am a clinician. I've been in clinical practice at Dartmouth Hitchcock for almost 20 years, and a large component of my time is spent taking care of patients with Lyme disease. I consider myself to be knowledgeable about Lyme disease. I've never had, taken any political action, I've never testified before a committee about this or any other topic. I have no interest other than to state my views about Lyme disease and for the public health.

I was asked by Dartmouth Hitchcock to come today to specifically address the issue of the bill. But this has been discussed at such length today, so I'm really going to put aside my comments almost completely.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Dr. Parsonnet: And just address a few issues. So many things have been said today that are untrue about both the Infectious Disease Society and about Lyme disease.

First of all, I can say that anybody can make guidelines and they can say, you have guidelines and we have guidelines, our guidelines are equal. And Dr.

Hunter and others have brought up books and books. I know what's in those books, I've read every article in every one of those books. Many of them are case reports and uncontrolled studies. There's not one controlled study. A controlled study means it's free from patient and physician bias. There is not one single controlled study that shows a benefit of prolonged antibiotic therapy. There's not one, okay?

<u>Senator Jacalyn L. Cilley, D. 6</u>: Dr. Parsonnet, are those under way currently with the IDSA?

<u>Dr. Parsonnet</u>: The IDSA is not a, just has no money. IDSA does not conduct clinical studies.

<u>Senator Jacalyn L. Cilley, D. 6</u>: Okay.

<u>Dr. Parsonnet</u>: Clinical studies are conducted by investigators. They are funded typically by the National Institute of Health and by drug companies. The IDSA has no ability to conduct clinical studies. Okay?

Now, I wanted to make a couple important points about Lyme disease. First of all, I would defy anyone to show me in IDSA guidelines saying that ILADS guidelines are substandard. The word substandard are not used in those guidelines. This is a fabrication, this is something that's being thrown about in order to make it look like IDSA has an axe to grind. A bunch of knowledgeable physicians got together, looked at the literature and they came up with this set of guidelines based upon their assessment of the best evidence. There's no comment in there about being substandard.

Now, I wanted to make something very important, important. People, IDSA has not said there is no such thing as chronic Lyme symptoms. Absolutely not. We know that people have Lyme disease and that they've been treated and they continue to suffer. And there are many of these things that are debilitating. People have neuropathic pain, difficulty with concentration and memory, mood disorders, and these are very severe. Nobody denies that. The question is whether, simply whether this represents active infection.

Now the preceding speaker used syphilis as an example. Syphilis is highly cured with antibiotics. Highly cured. Of all the examples to be given, this is the most bogus. Tuberculosis is cured with antibiotics. Bacterial infections, syphilis are treated and cured easily with antibiotics. There is no precedent for treating a bacterial infection such as Lyme disease with a prolonged course of antibiotics. And there is no evidence from carefully conducted studies that this organism persists following an adequate course of therapy. Dr. Donta, who's here representing the view in favor of this bill, acknowledges that Seftriaoxone probably isn't even working as an antibiotic. He said this is working in some way to, as a neurotoxic prevention. This is not an issue that requires antibiotics. We know that people have symptoms. We know that people deserve empathy and treatment.

Senator Jacalyn L. Cilley, D. 6: Dr. Parsonnet?

Dr. Parsonnet: Yes?

Senator Jacalyn L. Cilley, D. 6: We are getting into the realm of, you know, the disorder and treatment again, so...

Dr. Parsonnet: Okay, alright, I just want to say that, but it was ...

Senator Jacalyn L. Cilley, D. 6: I want to be fair to both sides, that's not why we're here.

Dr. Parsonnet: ...it was, it is an untruth that the IDSA does not believe there are chronic symptoms from Lyme disease. It's just we do not believe that there is evidence supporting long term use and antibiotics can be dangerous.

Let me say just one more thing about the bill specifically. The bill specifically says that Lyme disease includes an infection that meets the surveillance criteria as set forth by the National Centers for Disease Control and Prevention. Not the IDSA, not by Infectious Disease doctors, but by the CDC, whom I think most of us view as positive. Well, I looked at the CDC criteria, and for chronic disease there should be at least one objective evidence of late manifestation of Lyme with laboratory confirmation. So this bill takes a very vague definition of Lyme disease and says with symptoms that can be very non-specific, and says that we think that doctors who just write in their chart that they've diagnosed a patient with Lyme should be able to treat with an unproven and potentially dangerous therapy for an indefinite period of time. And this does not conform to what we think is a safe measure and would undermine the Board of Medicine's ability to supervise this important, treatment of this very difficult disease.

You know, I sort of have a lot of other things I want to say, but I really wanted to address those important issues of the dueling standards. **See written testimony of Dr. Jeffrey Parsonnet attached hereto and hereafter referred to as Attachment 7.**

Senator Jacalyn L. Cilley, D. 6: But please make sure our Committee secretary has that written testimony, and we will be looking at it.

Dr. Parsonnet: I've given it to her.
Senator Jacalyn L. Cilley, D. 6: Okay, I have a couple of questions.

Dr. Parsonnet: Yes, please.

Senator Jacalyn L. Cilley, D. 6: You are an infectious disease specialist?

Dr. Parsonnet: Yes, I am.

Senator Jacalyn L. Cilley, D. 6: Okay. Are you familiar with the history of ulcer treatment, which I know isn't an infectious disease presumably, but it is bacteriologically.

Dr. Parsonnet: It just so happens that my sister is one of the people who discovered the relationship between heliobactopilori and gastric cancer, yes.

Senator Jacalyn L. Cilley, D. 6: Interesting, okay. So, took it to another step, because in 1981 to 1983, Marshall and Warren investigated that. And do you know what happened over 20 years beyond that, the time that they initially discovered that with their first 100 patients?

Dr. Parsonnet: I'm not sure what you're specifically referring to, but I'm well aware of what's going on, yes.

Senator Jacalyn L. Cilley, D. 6: Well, they did the research. They wanted to present it at a major conference. They were told they couldn't present the research. Gastroenterologists called them crazy. They said that, you know, that no such thing could possibly happen. It took over 20 years before ulcer patients were treated with, you know, with antibiotics. You know, from a life of suffering on Tagamin, and my point is this. That there are times it's clear, while I may have concerns about what this bill is doing, would you agree that the medical profession is not always quick to embrace innovation or alternative approaches to the care of human beings?

Dr. Parsonnet: With respect, Senator, first of all, as you said, the study came around 1980. I was a medical student then and we immediately embraced this. So it was not 20 years before it happened.

But second of all, there's been no shortage of publication. There's been no suppression of this literature. Dr. Hunter presented two notebooks. There's been no suppression of this information. But just because it's out there doesn't mean it's correct. It doesn't mean we have to believe it. Of course, there's always resistance of anyone who's in authority, whether it's a taxi driver or a lawyer or a doctor. There's always resistance.

I learned when I was a resident, my professor told me, whenever something new comes out, the first people, the first thing people say is, well, it's not true. The second thing they say is, well, it's true but for the wrong reason. And the third thing they say is, well, it's true but we don't know that already anyway. Well, these papers have been coming out about Lyme disease now since 1979. And yet, 31 years later if my math is correct, there's no objective controlled evidence, okay, that prolonged antibiotics are of benefit.

<u>Senator Jacalyn L. Cilley, D. 6</u>: That leads to my second question.

<u>Dr. Parsonnet</u>: Yes.

<u>Senator Jacalyn L. Cilley, D. 6</u>: In terms of, is it your position that the distinction between IDSA and ILADS is that IDSA is looking for controlled studies, the double blind studies and all of that. And that ILADS is not producing that?

<u>Dr. Parsonnet</u>: I don't expect ILADS to produce it any more than I expect IDSA to produce it.

<u>Senator Jacalyn L. Cilley, D. 6</u>: Okay.

<u>Dr. Parsonnet</u>: But you know, a previous speaker said there's no evidence that's difficult to, there's lots of ways we can look for this organism. We can do cultures, we can do PCR tests. There's innumerable, not innumerable, but there are many ways in which IDSA, in which, why doctors have wanted to look for persistence of this organism and not found it. And yes, there are case reports of it and that's why IDSA in their guidelines say very explicitly, these are guidelines. Individual physicians should feel free to practice as they wish.

The fact that insurance agencies are not covering this expense in Connecticut, which brought about the lawsuit, that's not IDSA's doing. IDSA looked at the literature and came up with some guidelines. And it says on the first page in italics, I think, that this should not be a substitute for individual physician practice.

<u>Senator Jacalyn L. Cilley, D. 6</u>: Thank you. Are there questions for Dr. Parsonnet? Thank you very much. So we have Greg Kettmann next and then Gail Abarba, did I pronounce that correctly.

<u>Ms. Gail Abarba</u>: Yes, you did.

Senator Jacalyn L. Cilley, D. 6: Okay. Mr. Kettmann.

Mr. Greg Kettmann: Hello. So my name is Greg Kettmann. I collected the booklet that you have in front of you, some of you have in front of you. We issued five of them, the fact booklet. I put that together. If you have any questions on that booklet, please feel free to answer, ask those as well. I can answer those questions as well.

As far as the wording on the bill from the previous, that is taken very similarly to the Connecticut bill, which was passed unanimously as indicated by Representative Daniels.

Also, as you can tell, this issue is very contentious with a lot of differing opinions from both sides. We would like to avoid that debate. This is not about that debate. We don't want to get involved. This is about patient choice. This is about us having the ability to get care. Why is it so important to me? My wife, sitting behind us, on 12/31 of 2001, so I think that's eight years ago. My math could be slightly off. We went into the hospital here in Concord. She had chest pain. It was not her heart and that led to a continuous five years of seeing every doctor, that's Dartmouth Hitchcock, that's Boston, every doctor that was suggested to us, we went. Neurologists, I'm sorry, I won't get all the names right. We saw numerous specialists. My wife got worse and worse and worse. At the end of five years, there was one diagnosis of fibromyalgia and my wife was no better with no diagnosis. In fact, she was crippled. She could not walk up and down the stairs. I literally had to physically carry her up and down the stairs just to go to dinner. By the end, she couldn't even go to the restroom, the bathroom, 15 feet away, without my assistance. That's what these doctors are saying is an acceptable course of action.

At the end of that five years, we went to our doctor and we said look, we're worried about Lyme disease. He said no, we ran the ELISA test, it came back negative, no more testing. Three weeks later, coincidentally, I get a letter in the mail certified from my doctor, saying would you please find a new physician. Now if that's not intimidation against Lyme disease, I don't know what is.

The good news is, is my wife walked in here today. Why? Because she's been on antibiotics for three years. We go down to New York because there's where we have to go to get treatment to make my wife able to live through the days. Okay? That's a powerful story. The story we heard from all three doctors supporting the IDSA position is, no, everything's fine, nothing's

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broken. We don't want to solve the debate. All we want to do is get the care that we desperately need.

So why is it so important to us today? I'm going to take you through some statistics. All of these statistics are in the book.

Senator Jacalyn L. Cilley, D. 6: And we've seen them.

Mr. Kettmann: This chart, okay? If you can see it, is the incidence of Lyme disease in New Hampshire. I'll have you note that it went up 44 percent year to year. It's going to keep going up.

Also, by the CDC, they say that these cases, these are only the confirmed cases. If we look at their numbers, they say, depending upon which article, is six to twelve times more than what we're seeing. That's up to 19,000 cases in New Hampshire in one year alone. Okay? That's a problem.

Additionally, we hear about Triple EEE, West Nile and AIDS. Did you know that Lyme disease exceeds all of them, that's this chart, by a fair portion? More significant than all combined. In New Hampshire, these two maps, and again, they're in there. Are, one of them is tick infection rate, I could have it backwards. One is tick infection rate and one is diagnosed cases of Lyme. So these clearly correlate to each other. This year alone, there was an article recently. The State entomologists suspect that there are a three-fold increase in the number of ticks that they're seeing this year than before. Which means we're going to see an increase in this. We need our doctors to not be afraid to treat Lyme disease. And they need some form of protection. Just a little shield and that's all this is.

So the IDSA guidelines. That is not in the booklet, by the way. If you'd like, I can leave these with you.

Senator Jacalyn L. Cilley, D. 6: It's online.

Mr. Kettmann: The IDSA guidelines, feel free, it's online, that is correct. This is just a printout.

Senator Jacalyn L. Cilley, D. 6: I was browsing it this weekend.

Mr. Kettmann: Excellent, thank you very much.

Senator Jacalyn L. Cilley, D. 6: You're welcome.

Mr. Kettmann: They're somewhat restrictive. They do say four weeks of antibiotics. If not, they say it's not Lyme disease, it's not persistent infection.

These are the ILADS guidelines, okay? These are also evidence based, peer reviewed guidelines. All we're asking for is that available guidelines, two standards of care, be adhered to and that we as patients be allowed to make that decision. That the doctors be allowed to treat. We're not even saying that they have to advocate one standard over the other. But I want to be able to go to a doctor and say, look, would you test me more thoroughly for Lyme disease and now be dismissed from his practice. That's why we need this legislation.

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions for Mr. Kettmann?

Senator Sharon M. Carson, D. 14: Senator Fuller Clark.

Senator Jacalyn L. Cilley, D. 6: Senator Fuller Clark.

Senator Martha Fuller Clark, D. 24: Yes, thank you very much. Would you say, if the Board of Medicine were to publish on their website under their policies that they recognize that there are two standards of care for Lyme disease. And that as long as these two competitive standards exist, they are not going to bring physicians before the Board of Medicine for choosing either one of these standards?

Mr. Kettmann: The question is, actually there's two questions in that, the way I read it. Because that would be an excellent step. We'd love to see that, but that doesn't fix the fundamental problem. The purpose of this bill is to provide that protection. Yes, that would provide an element of protection, but other states. For example, when we go to New York. They have a bill in place, that's one of the reasons we can go there to get treated. The doctors need to see it and not just an assurance that we're not going to do it. This holds the legal weight. And again, it's very, very focused, as David Hunter mentioned. It's very focused. If, for example, they diagnose Lyme disease and they miss another diagnosis, they can still be prosecuted or punished or whatever. Did that answer your question?

Senator Jacalyn L. Cilley, D. 6: Follow up.

Senator Martha Fuller Clark, D. 24: The follow up question, though, is how do you respond to the concern that once we as legislators start providing protection in law for one type of treatment as opposed to another, that that just doesn't become a situation where we are continually being asked to step into the issue of standards of care?

Mr. Kettmann: I am absolutely opposed to government involvement wherever possible. However, right now, I know and from talking to dozens and dozens of patients, we are being denied freedom of choice in our treatment protocols. That is a fact. And even the people adhering to the IDSA viewpoint and talking about that, they're merely saying, well, we just don't think that's valid and all that. But the fact is, we're being denied care.

If you went in with cancer, they would give you a dozen different treatment guidelines. You could say, oh, I want chemo followed by radiation, or whatever. My sister had cancer and they literally listed a shopping cart. They said we could try this or this. Surgery followed by radiation, whatever, right? If you go in now for Lyme disease, you get one choice. It's in the IDSA guidelines, that's it. If four weeks of antibiotics have not cured you, you're done. You're done. If that were what I was sticking to right now, my wife would still be in bed.

Senator Martha Fuller Clark, D. 24: Thank you.

Senator Jacalyn L. Cilley, D. 6: Any following questions? Thank you very much. So Gail Abarba next, and following that, June Cormier please. Yes, okay. Thank you very much, Lou. We've been asked to ask the speakers to speak up. Folks in the back of the room can't hear the testimony. I'm assuming that's, Lou, having difficulty with?

Lou (unknown last name): Apparently everybody except yourself.

Senator Jacalyn L. Cilley, D. 6: Oh. I used to teach with 144 students in the room, so my voice usually carries. So, Ms. Abarba.

Ms. Gail Abarba: I'm the public member on the Board of Medicine. And as a public member, I'd like this body to know that I have no vested interest in the practice of medicine.

Senator Jacalyn L. Cilley, D. 6: You did not sign in either support or opposition.

Ms. Gail Abarba: I did, I signed in opposition.

Senator Jacalyn L. Cilley, D. 6: You signed in as speaking, but not in opposition.

Ms. Abarba: Oh, I'm sorry. I'm in opposition to this bill. What I intend to testify about is anecdotal evidence, such as was presented before and by Dr. Young, who talked about his daughter. This is evidence that was brought to me a couple of weeks ago. No one knows, this person did not know I was on the Board of Medicine, did not know I had any connection with the Board of Medicine.

They told me a story that I found very compelling. They had gone for treatment locally in the area for what they thought was Lyme disease. And they were not diagnosed and they had to leave the area, as somebody else had testified about. They went to Boston and they saw someone who claimed to be someone who could deal with Lyme disease. And they were given antibiotics ...

Senator Jacalyn L. Cilley, D. 6: They're referred to as Lyme literate doctors.

Ms. Abarba: Yes, Lyme literate. And they went to this person for four years and they were on antibiotics for four years. Now this person is claiming that after this four years of treatment, she is more debilitated than she was before the treatment. And she has come back to the local area and wants a doctor to give her some diagnosis. Which is: there is none. There is no diagnosis for it. But my point is, she is in a worse position than she was before.

And my fear is that if this passes, there will be more doctors setting up as experts in Lyme disease and giving people long term antibiotics. That we don't know what's going to happen when somebody's been on long term antibiotics. In fact, I talked to a general surgeon and he said he's seeing now a person with colon rectal disease who has been on long term antibiotics. And he thinks it's a result of that. I don't know, I'm not a doctor, I don't claim to be a doctor.

Senator Jacalyn L. Cilley, D. 6: And that's part of the problem with the testimony, forgive me, but ...

Ms. Abarba: Yeah, it is.

Senator Jacalyn L. Cilley, D. 6: Anecdotal information from third party sources, we should have records of that if they want to be heard in this setting.

Ms. Abarba: Right. And as Dr. Andelman has said, we, I am on the Board and we are in complete opposition to this bill. And I thank you for your time.

Senator Jacalyn L. Cilley, D. 6: Thank you, very much. Don't go yet. Are there any questions for?

Senator Sharon M. Carson, D. 14: No.

Senator Jacalyn L. Cilley, D. 6: Okay, thank you very much. So with that, I'll call June Cormier. And following June Cormier, I'd like to hear from, is it Joseph Toronto from DHHS, did I mutilate?

Dr. Jose Montero: I think, Jose Montero, but it's physicians writing, so.

Senator Jacalyn L. Cilley, D. 6: Oh, oh, you know what it is, you've got a T before that. I was going to say, I thought Dr. Montero was going to be here. Okay. So, June.

Senator Betsi DeVries, D. 18: I don't think she's coming forward.

Senator Jacalyn L. Cilley, D. 6: Is June Cormier here? Has she left?

Unknown: I think she left.

Senator Jacalyn L. Cilley, D. 6: So, okay, Dr. Montero.

Dr. Montero: Good afternoon.

Senator Jacalyn L. Cilley, D. 6: Good afternoon.

Dr. Montero: Jose Montero, Public Health Director of the New Hampshire Department of Health and Human Services.

I am here to testify in opposition to this bill. The reasons that the Department has to oppose that bill have been clearly expressed by the Chair of the Board of Medicine. Our big worry is that this sets a precedent and opens a door endorsing the use of non-evidence based medicine may remove some protection for patients and may become a back door way to legislate in how our standard of care should be.

You saw the data. We are the ones that provided the data on Lyme disease for the state. I guess you already have copies of those. One of the previous speakers showed those.

Senator Jacalyn L. Cilley, D. 6: We have them in our books.

Dr. Montero: And certainly we have, if not the highest this year, one of the highest rates of Lyme disease across the country. That's explained for a couple of different reasons. One, because disease is increasing. Certainly, we are seeing more and more Lyme disease, all in the Northeast, not just New Hampshire. At the same time, you have been doing a lot of education in providers so we can get an early diagnosis. Because that's the best time and best way to treat the disease, when it's early, so we can have more certainty that antibiotic treatment will properly work.

The other big change is that a couple of years ago at the national level, the CSTE, the College of State and Territorial Epidemiologists, modified the definition for Lyme disease and accepted, decided to accept as probable cases diagnostic testing that do not feel, do not fulfill the whole criteria expressed by CDC that a test should have.

When you look at our numbers and you see a jump in 2007 from 900 to 1,600 in 2008, more than 400 of those cases are what we call probable cases. Why was that done? Because we wanted to get a better sense of what is this burden of Lyme disease that may be misdiagnosed or undiagnosed out there. We know that there is a lot of people who may have been missed initially, because not all of the clinical symptoms are equally manifested in every single patient. And that some clinicians may not be thinking about Lyme disease early on and missed it.

There are some difficulties with the test. Tests are not perfect and we would all love to have a test that is always 100 percent right. But that, that's no exception. So how do we balance that? The decision was, include those that gives you a better sense of burden of the illness.

In our reports, clinicians actually tell us I have been treating this patient for two months, six months, and we have those reports in our office. So we know that our clinicians are providing that type of treatment in New Hampshire beyond the standards recommended by IDSA guidelines.

Senator Jacalyn L. Cilley, D. 6: Could I stop you there for just one moment, Dr. Montero? Because it's on a point that I'd like to ask a question on. Why does the Health and Human Services only list the IDSA guidelines? I mean, is there, do you not feel that the ILADS guidelines are as valid or do you have a question about those?

Dr. Montero: We certainly follow all the evidence based practice, and we have been strongly advocating for evidence based medicine and evidence based public health. That has been a big change from 20 years ago, when everything went.

Certainly, we like to see trials that show that giving a particular treatment is better than placebo. And that's the reason why we accepted and adopted the guidelines from IDSA and that's the reason why they are posted on our website. There is no other guideline that fulfills that particular approach, and that's the reason why the only guidelines that we have, and actually the only ones that are federally accepted, that was a term used before, are the ones from IDSA. Those set out by a group of experts at the national level, who reviewed the literature as explained by Dr. Parsonnet earlier. IDSA doesn't do the research. They collate the research done and funded through the CDC or INH or several other private groups. That's the only thing that we have that is tangible that we can feel confident that has the weight of science and evidence behind it that we can post on our website.

Now, we have not taken the position that this is the only thing that you need to. And in fact, we know that physicians and clinicians do practice as they feel their knowledge allows them to better treat the patient, and they are doing that today.

Senator Jacalyn L. Cilley, D. 6: But you would agree, would you not, that if somebody were to go to Health and Human Services' website, or the Board of Medicine's, or you know, the Medical Society, and they only see one set of guidelines, that that would have a certain biasing effect on their approach, would you not?

Dr. Montero: I certainly hope that that is the case, because the only reason why those are posted is because those are the ones that have science behind.

Senator Jacalyn L. Cilley, D. 6: Okay, just so that the Committee is clear, the research by IDSA suggests that the studies that they have formed their opinion on are, what's the word that I'm looking for, more than evidence based. They are statistically more ...

Dr. Montero: Significant? That's part of the issues here, and I want to acknowledge something that one of you Senators asked before. Medicine does change.

Senator Jacalyn L. Cilley, D. 6: Reluctantly, from what I can see.

Dr. Montero: Thank God it does change. And change is not always quick to come. At the same time, we need to be incredibly careful in how we accept and adopt those standards. Not because somebody or a group of people just come say, this is what we believe should be done, should be done.

Now, when you look at federal standards, there are different categories of the standards, A, B, C, D. There are some where there actually is not enough evidence in the literature to recommend one way or another, and they are rated with, I think, maybe a C. That is expert consensus. There is a type A recommendation, when you look at clinical studies, double blind where people got this or the other and all the evidence shows that this treatment works. We don't have that for patients with chronic manifestations of Lyme disease. And I want to emphasize those terms. Chronic manifestation of Lyme disease, we have known those from the very beginning. In fact, Lyme disease was diagnosed after patients had arthritis, and that's the way that it was found. So we have always known that Chronic manifestations of Lyme disease do exist.

We have today a huge group of people that is suffering, and I don't want to not validate that. These are people that are ill, we just don't know what they have. If it's Lyme or if it's not, I don't know that. I don't know if the clinicians know that and we all want to do the best that we can for those patients. And some people think that maybe giving them antibiotics for several years is the right way to go. I don't have, as a policy person in the Department of Health, enough evidence to support that approach. Which does not invalidate the pain and suffering that this population is having. It's just that I don't have the tools right now to validate one approach that is being advocated by some people.

Senator Jacalyn L. Cilley, D. 6: Are there questions for Dr. Montero? Senate DeVries.

Senator Betsi DeVries, D. 18: Thank you, Madam Chair. Dr. Montero, the studies, double blind or whatever, the criteria that you would find to be appropriate. Why are they not being conducted by the CDC? Is it not being funded?

Dr. Montero: Actually, there are a couple of studies that look into long term antibiotics. I think that maybe four studies have been done that way, and they show improvement in long term antibiotics being equal to placebo. So, yes, there are people that improve with long term antibiotics at the same rates that they improve with placebo.

And today, understanding the placebo phenomenon is extremely complex, because in the past used to think, oh, just give sugar pill and people will have the same. No. Placebo today will look at it in different ways. People require real medication and for whatever reasons that are right now beyond full explanation, they improve with the treatment that may not offer that much of an advantage. And that's a tricky thing that somebody needs to resolve. I am not a researcher. This needs to be done. We need more research in Lyme disease, absolutely. We need more research that allows us to find what the answers are for these people that are suffering with this debilitating chronic condition. We have several of those conditions over the years. We have the fibromyalgia, chronic fatigue, several of those patients have come with a different diagnosis. I don't know if all these patients that today are called chronic Lyme disease will call with a different diagnosis as science progresses. My guess is that it will, I just don't know when. And certainly, they are suffering today.

Of course, every clinician would like to help them. What's the right way? I will leave that to the clinicians, not to a legislature is that, covers a particular approach only for those particular groups. It opens a lot, what's the next condition that we're going to see under the same umbrella where we're asked as a policy issue of the Department?

Senator Jacalyn L. Cilley, D. 6: I'd like to jump in on that one. I am not sure if you've got a follow up, Senator DeVries. But you're touching on a point that's of particular interest to me. Dr. David Newman, in his book, *In Hippocrates Shadow,* had a whole section on placebo effect. So you know as a physician, I'm sure, that knee surgery actually has been proven to be pretty ineffective in most instances. And yet, when you put somebody under anesthesia and you pretend to do knee surgery and you put a couple of holes in their knees, they walk again the next day.

So there are, there's case after case after case of medical approaches that are being used for which there are no double blind studies and there is no compelling evidence, looking at the Cochran collaboration, and yet you're all using it. So I guess my question is, when you have people who are suffering and who, for the traditional approaches, your medical professionals have not found anything that works. Why would you not at least offer these people an alternative for which some of them have been proved?

Dr. Montero: This legislation doesn't offer that.

Senator Jacalyn L. Cilley, D. 6: I'm not asking about the legislation, per se. I think the legislation would never have been brought forward if you had put on the website at Human Services, there are different thoughts about the treatment for this and doctors can, you know, should be free to practice as long as they've done due diligence. I think that's one of the concerns in the literature that I read and a lot of the testimony in the House. It was that, you know, if you won't even put up an alternative on, you know, Health and Human Services' website, this says to a physician, you know, we're not recognizing this treatment in New Hampshire.

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Dr. Montero: Actually, a couple of interesting points there. First, with the placebo effect and the knee surgery example. Actually, there was some initial data, the one that was used to license that type of procedure, we are going to see that more and more for anti-depression medications. That when you compare those in the overall population, there are groups that do not benefit from that. So maybe they're going to be selected and more selective for some particular types of people. I don't know if they do have all the evidence to do those things about those particular procedures.

The Department of Health and Human Services doesn't treat patients. We don't treat patients, we do surveillance. We follow them and make sure that we understand what's the geographic distribution and burden of illness. And we provide in our website access to fairly accepted guidelines. We don't make those decisions for which ones are fully accepted by the national groups, organizations or academic powerhouses. Certainly, I do acknowledge that some of those have some vested interest and they are not necessarily the fastest to move. Which actually may be appropriate, because we are talking about human lives and we can not just jump every time that somebody comes with an idea, and give it to everybody.

The Department doesn't treat patients. We don't tell clinicians how to practice. That is the domain of peers and the standards of practice. Our worry as the Department with this legislation is opening the door for accepting things that are not vetted, properly vetted, scientifically proven, and removing patients' protections. How the clinicians practice is something that we don't tell them how.

Senator Jacalyn L. Cilley, D. 6: Okay, so I think the bottom line is that you're saying that there's greater evidence on the IDSA studies than there are on ILADS and that's something that ... Senator Carson.

Senator Sharon M. Carson, D. 14: Thank you, Madam Chair. I found what you just said very interesting, Dr. Montero. In that you said something about opening the door. And unfortunately, I think what's happened is that the medical community has actually opened this door because you can't seem to make up your mind about what is an appropriate form of treatment for this particular disease. And that's why, I think, people have come here to the Legislature and they're asking us to intervene in this process.

I've sat here very patiently and I've listened to a lot of the testimony so far. And quite frankly, in another life back in the early 1980s, I happened to belong to an Army Reserve unit that did a lot of the initial work on Lyme disease. I mean, we were the folks that were out in the woods catching ticks to test them. So I'm very familiar with this issue and I'm also very familiar with the long term effects of Lyme disease. And I think you've heard a number of suggestions that have been voiced, not only by Senator Cilley, but by Senator Fuller Clark, about why can't you just put something up on the website? To recognize the fact that there is no consensus on how to treat this disease, and allow the physicians with their patients to make the best choices for those patients?

Dr. Montero: Madam Chair, I will respectfully disagree with a couple of those statements. First of all, there is consensus. What we don't have is unanimity and those are two different things. The scientific community has consensus about how to treat Lyme disease, and those are the ones that are published in the IDSA guidelines. You will not have everybody 100 percent of the time agreeing on those, and that's a whole different thing. But there is unanimity versus consensus. Consensus, they agreed to those, they disagree with some people. If they choose to have minority reports or not, that's a whole different thing.

So, again, we certainly look at people that have a lot more bench strength than we have in our department. We look at the federal level, we look at NIH, we look at CDC for guidance. As well as we look at the consensus at the academic level, in what the right treatment for a condition is. Again, we don't tell physicians how to practice. That's not our role, we are not telling them that. We are only doing surveillance. When we discuss with them approaches or they want our advice, we send them to infectious disease clinicians that we have on our team and they discuss those options of treatment. If they don't agree or if they want to follow and do longer treatments, actually they do. And they report that to us. It's not that they are doing this in secret. I have those reports, when they tell me, I have been giving this patient six months of antibiotics. That's their prerogative as clinicians and that's where the decision should stay.

Senator Jacalyn L. Cilley, D. 6: Are there further questions for Dr. Montero? Okay, seeing none, thank you very much.

Dr. Montero: Thank you.

Senator Jacalyn L. Cilley, D. 6: I'm going to call up the next two people, then I'm going to give this Committee and staff a 10 minute break. So with that, Jacqueline Arlen and Marie Velselsky. Hopefully I haven't mutilated that name. Or Marie Velselsky next. So starting with Jacqueline Arlen.

<u>Ms. Jacqueline Arlen</u>: My name is Jacqueline Arlen, and I'm here today with my daughter Victoria. She has advanced chronic tick borne infection, we try not to ...

I think it's important that you understand what has gone on these last five years. Before I briefly tell you our story, I'd like to emphasize what I feel is very valid and needs to be made point today, is that we can argue back and forth all day along about the use of long term antibiotics and protecting our New Hampshire doctors. But at the end of the day, I believe it's about patient advocacy. If our doctors are made to, were made to feel more comfortable about treating patients with Lyme, we would get more doctors involved and maybe possibly even learning about the infection. What we as patients need are more doctors in this state who are willing to listen and at least try to, attempt to try to help us. We as a family were alone, and with only one Lyme doctor advocating for us. And he's now no longer practicing in this state, because of the pressures that were subtly put on him in his practice. And Tory has damage to her spine because of this infection, and this could have been avoided had her primary care practitioner just believed her in the first place, and treated and tried to help us. She has completely lost these years of her childhood and these are years that she'll never get back.

Our journey began in March 2005 and she was bitten by a tick. I brought her to her pediatrician with a red swollen ear and was given cortisone cream and sent on our way. What I did not realize was that the doctor had noticed a small puncture wound in her ear and made a note of it in the chart, that it was a possible bug bite. But had neglected to tell us, so what followed was actually a textbook case of Lyme. That following year, she had flu, high fever, fainting spells and all kinds of strange ailments. And I'm sure that you are aware, with Lyme disease it's quite curable if found caught early and antibiotics are given. She was back in the pediatrician's office every few weeks and months, and she was a child who maybe once a year went for well check ups.

Because we never knew there had even been a bite in her ear, we just assumed her immune system was out of whack. Despite all this, Victoria continued to excel in everything she did. She just was saying, I just don't feel right. What happens with this infection, if left untreated, it goes into advanced stages, which we've discussed. And this is exactly what happened to Victoria. And then on April 29th the next year, she woke up in terrible pain on her right side. And after a few days, it was assumed to be appendicitis and her appendix was removed. She never recovered after her surgery. Within weeks, she had lost 15 lbs., her legs started to give out on her and by the middle of June, she was paralyzed and we were ordering the

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wheelchair. She started to have trouble swallowing and we were losing her cognitively, all the while she was in insane pain 24 hours a day. She used to cry herself to sleep and even cry in her sleep. It would take doctors eight months before a pain team took the time to diagnose it as neuropathic and at least started to treat the neuropathic pain.

Her doctor who had had her as a patient since birth and had missed the obvious, said she was doing all this for attention because she's a triplet. It was all in her head and Victoria was incredibly insulted by this. We were watching her fail and we were alone, and it was taking a huge toll on our family. By the middle of July, she lost her memory, did not know who we were, who she was and where she was. Can you even begin to imagine what it is as a mother to have her look right in your eyes and not even know who you are? We had four major stays in medical institutions and the doctors were of no help. And after minimal testing, unbeknownst to us, they all were going down the psychiatric treatment route. I will not get into details of what a horrible time that summer in a prominent Boston hospital, but what they did to her was horrific.

To this day, our family is brought to tears at the thought of how we almost lost her at the hands of the best in the world. I would like anyone who has children to imagine for a moment what it is like to hold your limp, unresponsive dying child in your arms and have no where to turn and no doctor to help you.

And this past year, when she had a relapse, we chose not to go to New York or Mass, but went up to Dartmouth. The same thing happened again, and we were discharged after eight weeks. They had done every test under the sun hoping to prove that she didn't have Lyme. They came up with nothing, nothing. We were discharged with mis-, undiagnosed. And I went home once again with a limp, unresponsive child.

I would like anyone, after major perseverance and research, we realized she did have Lyme. She was diagnosed by the doctor who no longer treats. What is amazing to me is that doctors acknowledge that early Lyme disease exists and that a course of antibiotics should work. They won't acknowledge that cases like Victoria that are missed and turn chronic. I challenge any one of you to look into my daughter's eyes and tell her that what she has does not exist. To this day, Victoria is fighting the fight but does it with amazing grace and has a spirit that melts our hearts. I will continue to advocate on her behalf and our dream is that other children in this state will not have to suffer as she has. **See written testimony of Jacqueline Arlen attached hereto and hereafter referred to as Attachment 8.**

Senator Jacalyn L. Cilley, D. 6: Thank you.

Ms. Arlen: Thank you.

Senator Jacalyn L. Cilley, D. 6: Are there questions for Ms. Arlen? Seeing none, thank you very much. And the last speaker for the moment, Marie Vel..?

Ms. Marie Veselsky: Veselsky.

Senator Jacalyn L. Cilley, D. 6: Veselsky.

Ms. Marie Veselsky: Good afternoon.

Senator Jacalyn L. Cilley, D. 6: Good afternoon and welcome.

Ms. Veselsky: My name is Marie Veselsky, I am a certified diabetes educator and a Registered Dietician, and have worked in healthcare for over 20 years. I currently work as the coordinator for the Diabetes Center at Speare Memorial Hospital in Plymouth, New Hampshire. I have been there eight years.

My testimony today is for the doctors in New Hampshire who should be able to practice without fear of reprisal for prescribing longer term antibiotics for Lyme. I personally do not know how long someone should be on antibiotics for Lyme, the magic time frame. What works for one person may take longer for another. The doctor, along with his or her patient, should be able to make that decision. I do believe, though, that the longer term antibiotics saved my life.

I never fathomed in my wildest dreams that it would take me 11 months to be finally diagnosed with Lyme. Eleven months to finally get one course of antibiotics, all because my first Lyme test, the ELISA, was negative and my second Lyme test, the Western Blot, was CDC negative. I believe the current testing and treatment guidelines allow people to fall through the cracks.

Starting in June 2005, interestingly enough, the young lady before me was March 2005, I had started having severe night sweats, fast heart rates of over 130 just standing, heart palps at night so bad that if I laid on my side, I could hear my heart pounding loudly in my ear. And thus I often slept sitting up in a chair. Muscle aches, unexplained bruising, shortness of breath just walking up a few steps. Exercise intolerance, dizziness, insomnia and extreme fatigue. A former long distance runner who just months before was setting records in my age group at road races. Yet because there was no abnormal labs, including the Lyme test, and all heart tests came back normal except for sinus tachycardia, fast heart rate, and insignificant T wave changes, I did not get diagnosed with anything.

April 2006, almost 11 months after my symptoms began, I found out that Lyme tests are not always accurate and I gave Lyme another look. A family physician did extensive testing and I was finally clinically diagnosed with Lyme. At first I was just glad I knew what I had, then months of "herxing" so bad I could barely get out of bed. The antibiotics were obviously hitting their mark. I obviously had some type of serious bacterial infection that the lab tests did not pick up. I was on consistent antibiotics eight months, from May 2006 to January 2007.

Now it is April 2010. Status post antibiotics, three years and four months. I never thought I'd be able to say that – three years and four months after antibiotics. I am well again. No longer will I take for granted the things I lost, like the ability to sleep, walking up a flight of steps without being out of breath, muscles pain free. I am able to run again every day and I feel very lucky. I ran the Mount Washington Road Race June 2008, about one year after stopping antibiotics. This was from a woman who could not climb three steps without being out of breath before getting the antibiotics I needed. I ran the five mile Red Shoe Barn Race last Sunday. I have also made the lottery for the Mount Washington Road Race June 19, 2010.

Why do I do this, you ask? Because I celebrate being given another chance at life. Many people are not so lucky. It would be easy just to move on with my life, now that I am feeling better. Forget about what a long journey it was to get the care I desperately needed. But I remind myself that I was out there once, hoping that someone would help me. I feel it is my obligation to help those people that may fall through the cracks like I did. And I also wanted to support my doctor. My doctor stuck his neck out for me. I am here today, literally, because of him. I am a race director for a half marathon on Plymouth coming up in July. It benefits the Pemi Youth Center, which is an after school program and the homeless shelter. I can give back. I am able to do this because my doctor did the right thing, even though he was going against the standard guidelines.

What I have always found interesting is that for a disease that is supposedly does not exist, chronic Lyme, there sure seems to be a lot of people who know someone affected by it. Your neighbors, your co-workers, a friend of a friend. I am sure you want them to get the help they need. Please protect a doctor's right to make clinical judgments about the diagnosis of Lyme and the length of time patients are on antibiotics. Again, I was on antibiotics eight months.

I know without a doubt three weeks of antibiotics would not have been enough for me. **See written testimony of Marie Veselsky attached hereto and hereafter referred to as Attachment 9.**

Senator Jacalyn L. Cilley, D. 6: Thank you.

Ms. Veselsky: Thank you.

Senator Jacalyn L. Cilley, D. 6: Are there any questions for this ...? Okay, thank you very much.

Ms. Veselsky: Thank you.

Senator Jacalyn L. Cilley, D. 6: With that, we are going to recess the hearing until 3:15. The staff needs a little break, I think, as do we. When I come back, we are really going to have to speed this up a bit more. I mentioned it before, but we have about 30 more speakers and I would prefer that you're not speaking to an empty room. But we'll see you at 3:15.

Hearing recessed at 3:05 p.m.

Hearing reconvened at 3:18 p.m.

Senator Jacalyn L. Cilley, D. 6: Reopen the hearing on HB 1326. We're going to continue to plug away. I'm going to ask again, please, and I know that sometimes, for many of you, you're not accustomed to this process. It is difficult to ad lib. I'm going to ask you to please just turn those letters upside down. We just, we've lost two committee members to other commitments. They've got other hearings going on. I believe we're about to lose at least one or two more shortly. So I once again want to emphasize, please do not read that written testimony. Give it to our secretary and summarize the key points.

So with that, we will start with Carl Tuttle and right behind him, Jessica Wojenski. Carl Tuttle? Carl Tuttle? Going, going. Okay, Jessica Wojenski. Good afternoon, welcome.

Ms. Jessica Wojenski: Hello. I would just like to start off by saying that I am proof that long term antibiotics work and that I didn't meet the criteria for those clinical testing that the IDSA held. Because I've never had a positive blood test and I never had the rash. But after my doctor clinically diagnosed me based on my symptoms, I had an initial Herxheimer reaction upon starting antibiotics, which indicated that I had Lyme disease. And I have now been on treatment for a year and I am confident in saying that if I had been taken off those antibiotics after 30 days, I would not be here before you. I would be bedridden and shut into a dark room and my quality of life would be next to nothing.

Since my treatment, I've learned how lucky I was that my doctor could diagnose me, because there are very few doctors in New Hampshire. And I actually almost had to go out of state to get treatment, because my doctor was so overbooked with Lyme patients and it was nearly impossible to make an appointment to get the next round of my treatment.

I asked my doctor if he was worried about losing his medical license and he said that he was, but that the benefits of treating and helping people such as me were worth it. And he was willing to risk his license to see people like me get better. But he is worried about it. And there are only a handful of doctors who treat the chronic Lyme in this state. The others who don't either don't know there's two standards of care exist, like was mentioned before. Because it's not on the website and they're just unaware that there's two standards of care. And they're afraid to stray from the CDC guidelines because of the repercussions that we've seen in other states, of doctors losing their licenses and just being reprimanded for their choice of care.

They say they're against the use of long term antibiotics because of the side effects that they can cause. But when you are faced with a life reduced to being in bed, it's worth it to take those side effects from the antibiotics, to see yourself getting better. I've had repercussions from the antibiotics, but I would much rather deal with those than the state I was in before I received treatment.

And I just believe that this bill is important because it gives, it will give doctors the option to inform their patients of those different standards of care, which they don't do currently because they're afraid to do it. If my doctor had followed the IDSA guidelines, I wouldn't be here because after 30 days of antibiotics I was still bedridden, I was still miserable and he knew that I needed to continue my treatment in order to get better. And it has now been one year since I started treatment.

I'm here on behalf of all the other patients who could not make it because they're in the same situation I was in a year ago. And I'm here in a proactive measure to prevent doctors in this state from ever having to face the incriminations that others have had to face. And if this bill is passed into law, other doctors in the state will not be afraid to take on patients with Lyme disease, and they will be more inclined to become educated on the two different standards of care and on the disease itself.

I want to bring up the example of the AIDS epidemic back in the '70s.

Senator Jacalyn L. Cilley, D. 6: I'm not sure that's relevant, Ms. Wojenski.

Ms. Wojenski: It's because of the ignorance and misunderstanding that was brought about during, there was just a general lack of knowledge within the public. And now 40 years later, we finally understand this disease.

Senator Jacalyn L. Cilley, D. 6: Oh, I see where you're going.

Ms. Wojenski: Yeah, I just don't want to see Lyme disease, I don't want to have to wait 40 years for this disease to be as widely understood as AIDS is today. That's the only point I was trying to make.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Ms. Wojenski: And I just believe that this bill is the first step. It's not going to cure the problem of Lyme disease and its controversies by any means, but I believe it is the first step in a long road and it will send the right message to the public, to doctors and to Lyme patients out there that things are being done to help these people. **See written testimony of Jessica Wojenski attached hereto and hereafter referred to as Attachment 10.**

Senator Jacalyn L. Cilley, D. 6: Thank you, thank you. Are there questions for Ms. Wojenski? Thank you very much.

Ms. Wojenski: You're welcome.

Senator Jacalyn L. Cilley, D. 6: I'd like to call Peter Ballou and Tony Fallon next. Has Carl Tuttle come back into the room?

Mr. Carl Tuttle: Yes.

Senator Jacalyn L. Cilley, D. 6: Okay, I will take you right after Tony Fallon.

Mr. Tuttle: Thank you.

Senator Jacalyn L. Cilley, D. 6: Okay.

Mr. Peter Ballou: I'd really like to read this. It's only 2 and a half minutes, please.

Senator Jacalyn L. Cilley, D. 6: Yes.

<u>Mr. Ballou</u>: Alright, this is going to be hard. My name is Pete Ballou and I have Lyme Disease, chronic Lyme. My non-Lyme literate doctors misdiagnosed me for three years. This was Dartmouth Hitchcock. During that time, my vision changed radically, I progressively became confused and developed memory loss and severe tremors. My balance and coordination became so bad that I was bedridden. I have been in the hospital emergency room twice in the last year. I've not worked in over a year and had to stop driving.

I stopped doing every activity that I have enjoyed in my life. The doctors would not investigate the possibility of Lyme disease, and I had to get a Western Blot test outside of my medical system. I had to change my primary care physician after he refused to acknowledge the Western Blot test results. Dartmouth Hitchcock treats only by the IDSA standards. They never made me aware of the fact that there was a complete set of standards out there, okay? When I discovered that on my own, I went and got my own Western Blot test and they refused to even acknowledge it even existed. That's one of the top neurologists from Dartmouth Hitchcock, literally laughed in my face when I showed him my positive test results of the Western Blot test.

There are only a few Lyme literate doctors in New Hampshire. Mine did a thorough workup on me and he has helped me to improve my overall health, as well as treat the Lyme disease, something that my previous doctors failed to do. My other doctors never told me about ILADS guidelines. I was never given a choice. They even refused to give me Western Blots. They just told me that they didn't know what was wrong with me and I would have to learn to live with my condition.

My Lyme literate doctor is the only one out of 15 doctors that I've seen who have said that he can help me get better. I've been on long term antibiotics since January of this year, and I feel I'm slowly getting better. I can't put in a full day's work yet, but I'm looking forward to that day. I finally found someone who's willing and able to help me. I'm very concerned that he may some day have his license taken away for treating Lyme disease with long term antibiotics. My doctor is also concerned that if this legislation doesn't pass, he will be targeted.

Please keep in mind that New Hampshire has the highest Lyme disease infection rate per capita in the country and the charts are going straight to the moon. House Bill 1326 does not shelter doctors from responsibility. It will offer a choice. By passing House Bill 1326, you are not only insuring the safety and proper treatment of Lyme disease sufferers in New Hampshire. It will also create an environment where other doctors would feel safe to become Lyme literate too.

Thank you for listening to me, because I feel that the last part of this is the most important. We need to create an environment where other doctors will treat this disease properly. Thank you for your time. **See written testimony of Pete Ballou attached hereto and hereafter referred to as Attachment 11.**

Senator Jacalyn L. Cilley, D. 6: Mr. Ballou, thank you. And you were very succinct. Are there questions? Thank you very much.

Mr. Ballou: Thank you.

Senator Jacalyn L. Cilley, D. 6: Tony Fallon followed by Carl Tuttle.

Mr. Tony Fallon: Madam Chair, if I may, I've mine under three minutes, so if I could read from the script, I'd appreciate the same.

Senator Jacalyn L. Cilley, D. 6: Can't summarize it?

Mr. Fallon: I could summarize but it would take longer. My name's Tony Fallon from Strafford. And I have been dealing with Lyme disease for 30 years. Four out of five of my family members have Lyme and I find the topic like being in the Wild West. Thank you for your service. I also thank God for the many blessings that we are showered with.

We plead with you to construct the shelter that House Bill 1326 will provide to doctors to enable them the freedom to fully practice. The dark hat opposition rests in the four sound bites of science, danger, limiting malpractice and legislating medicine. I attest and assure to you that the white hat doctors of ILADS, who do recognize the existence of long term Lyme disease, do so based on internationally recognized science. I further attest and assure that black hat efforts to forbid the recognition of Lyme disease is the true and real danger. It is also a crime and a sin, as it allows this disease to go from a total cure to a lifelong, life changing, life threatening plague.

I further attest and assure you that there is nothing in this legislation that limits recourse for genuine malpractice. I find the questioning today saying that this disease would give somebody escape if they did something wrong is specious, it's just absurd.

The final sound bite of legislating medicine is an attempt to scare you into thinking that you're becoming responsible for healthcare decisions. Take heart, this is an absurd claim. Instead of pleading with you to legislate a shelter for good doctors with white hats of ILADS to protect them from the black hat attempts to keep them from considering more than one standard of care.

As an architect, I create shelter for people to operate. Bill 1326 would provide the needed shelter for doctors to optimally treat this dastardly disease by enabling them to consider all possible protocols. If the situation wasn't so tragic, the absurdity of this black hat IDSA effort would be great comedy. Mandating one standard of care is like requiring that all buildings must be built with one material.

Senator Jacalyn L. Cilley, D. 6: Mr. Fallon, if I could stop you for a moment.

Mr. Fallon: Sure.

Senator Jacalyn L. Cilley, D. 6: I don't think it advances our needs to characterize some as, you know, valiant, and others... If you would refrain from doing that, I would appreciate it.

Mr. Fallon: That's all right, I'm sorry. As to the question as to why this is something that needs to go through the Legislature and not the State Medical Board. The answer is simple. As you heard today by the Medical Director, he was endeavoring to convince you that proper treatment for Lyme disease doesn't exist. Bill 1326 will build a shelter for what has been, okay, I'm getting off the task here.

I further attest and assure you that I know doctors have not shown up to testify due to fear for their careers. I've driven to hundreds of appointments in Connecticut and New York and at one time we had out of pocket costs of $3,000 per month.

Please construct the 1326 shelter to enable doctors the freedom to fully practice. The Connecticut State Senate voted the same bill up unanimously. It's a fitting suit to follow. Thank you. **See written testimony of Tony Fallon attached hereto and hereafter referred to as Attachment 12.**

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions? Carl Tuttle. And following Carl Tuttle, Julie Hall. Is Julie here?

Ms. Julie Hall: Yes.

Senator Jacalyn L. Cilley, D. 6: Okay.

Mr. Tuttle: Good afternoon.

Senator Jacalyn L. Cilley, D. 6: Good afternoon.

Mr. Tuttle: I'm Carl Tuttle. Thank you for allowing me to testify in support of House Bill 1326. My entire family was stricken with Lyme disease, my wife, my daughter. And I too have to read this, it's two minutes, three minutes, I promise.

My ordeal began in 1996, when at that time the Lahey Clinic diagnosed my exhaustion as chronic fatigue syndrome. I chased an unresolved fatigue for 12 years while ping pong through the medical community, never receiving a Lyme test. I was evaluated for a possible mitochondrial disorder at Tufts New England Medical Center as my energy production was extremely impaired. Over that 12 year period, I spent in excess of $60,000 trying to figure out what was wrong with my health. By the time it was properly tested in November 2008 through a Western Blot blood test, I was bedridden, on oxygen and completely disabled. I am fortunate to have a Lyme literate infectious disease specialist who treats late stage or chronic Lyme disease with long term antibiotics. My long standing untreated infection affected my heart, liver, joints, muscles and cognitive function, which ended a 25 year high tech sales career.

After 16 months on antibiotic therapy, I no longer require oxygen and I walk 20 minutes per day. I have a long road to recovery and at this point due to the length of time without proper diagnosis, but I honestly don't know if I would be here today if Lyme specific antibiotic treatment was not prescribed long term.

My wife has had joint pain for five years, diagnosed as fibromyalgia. Her pain was especially bothersome in both knees, to the point where walking up stairs was extremely uncomfortable. We attempted to treat her aching joints with supplements but experienced only limited success. She was often fatigued after work and fell asleep shortly after dinner. A Western Blot Lyme blood test revealed antibodies to Lyme disease, identifying an active ongoing infection. She has been on long term antibiotics 11 months for chronic Lyme disease and her so-called fibromyalgia is non-existent. I would like to point out that her Dartmouth Hitchcock primary care physician, who is not Lyme literate, refused to order the more specific Western Blot test after her ELISA Lyme test came back negative. The ELISA is less than 65 percent accurate, so those physicians who are unaware of the testing flaws usually provide an inaccurate diagnosis.

Our daughter has always been a happy child with exceptional grades, so when we experienced a serious change in mood, we knew something was drastically wrong. She became short fused, angry or irritable all the time, with mood swings, depression and developed a combatant behavior. These symptoms, as we have since learned, are a result of psychiatric Lyme disease. Once again, a Western Blot Lyme blood test revealed antibodies to Lyme disease identifying an active ongoing infection. She is the only family member who actually had a deer tick imbedded in the abdomen, but she did not develop the rash. None of us developed that class of rash, and we have found here in New Hampshire that in the absence of that rash, Lyme is the last thing the doctors will suspect.

Long term antibiotics for chronic Lyme disease has given us back our happy daughter, who is more patient now with no freak outs, as we call them, otherwise known as Lyme rage. My daughter's primary care physician, who is not Lyme literate, called to inform her that she didn't have Lyme disease based on lab results alone, without seeing her or considering clinical symptoms whatsoever, and that in my opinion is medical malpractice.

Our family is being treated by a Lyme literate doctor, who we are grateful. Please support House Bill 1326 intended to protect doctors. And we should include nurse practitioners as well, who specialize in treating Lyme disease, so we don't lose that limited valuable resource that we currently have available.

Lyme disease is only controversial until you experience it yourself. In closing, I would like to comment that the medical professionals here today in opposition of House Bill 1326 mostly likely have never treated a late stage Lyme patient. So I ask that you please keep that in mind when listening to the testimony. **See written testimony of Carl Tuttle attached hereto and hereafter referred to as Attachment 13.**

<u>Senator Jacalyn L. Cilley, D. 6</u>: Thank you, Mr. Tuttle. Are there questions? Okay, I'd like to call on Julie Hall next. And following Julie, Barbara, is it Hocci?

<u>Ms. Barbara Flocco</u>: Flocco.

<u>Senator Jacalyn L. Cilley, D. 6</u>: Oh, it's F-l, oh, okay. So Julie.

Ms. Hall: My name is Julie Hall. I'm here because I was infected with Lyme disease, as were three of my children within the last six years. We live in Rockingham County, which you've heard has the highest incidence of Lyme disease in this state, and where more than 50 percent of the black legged ticks are suspected to be carrying the spirochete that causes Lyme. It's a very scary place to live right now, my town.

Although four out of five of my family members have had Lyme disease, it's my son Tucker, my oldest boy, that I'd like to share his story with you. My Tucker, who was a straight A student, who was an All Star baseball player, first, third and pitcher, who was the guy with the ready smile and a can do attitude. My Tucker who you would never have recognized by that description a few years ago.

Tucker, who was diagnosed with Lyme in 2004, 2004, and two years ago had to be carried to the bathroom, missed six months of school, ended up in a wheelchair and had numerous invasive procedures because doctors again in New Hampshire, and even doctors in Boston at some of our best hospitals, refused to believe that his symptoms might be connected to his earlier Lyme diagnosis. Tucker, who is healed today, and I don't use that word casually, he is healed and he is well. He's a freshman in high school, he skied on the varsity ski team, he's getting ready for baseball, he goes to school every year (sic) and the only reason, and he hasn't been on antibiotics now for a year. He has no symptoms left going from so sick. The only reason is because a Connecticut doctor was courageous enough to treat his symptoms, despite threats, definite threats, to his own medical license for doing so.

Tucker was originally treated in 2004 according to the infectious disease guidelines, by my doctor. It states that, as you've heard, that the two to four weeks of antibiotics is effective. And I dare any of those doctors who spoke earlier to look at my son after three years, see him in bed, see him in a wheelchair and tell me that chronic Lyme does not exist. My doctor at the time did not inform me that there was another set of guidelines. He did not give me the option to choose how best to treat my son. And because there was only one set of guidelines on that website, I didn't know the options were available to me.

That winter, my son became symptomatic again. He was put on a course of 12 weeks of antibiotics by a nurse practitioner who had done her work, and now recognized that the Lyme bacteria had not been eradicated the first time. It was undertreated she said, and he was getting quite sick. But he got better again, until 2007 when during football season, he got sick. He had intestinal flu, he had symptoms of dizziness, he had headaches. One doctor thought it was the flu but it didn't get better. Then he thought it was stress, then he thought it was celiac. Then maybe, when he didn't get better, he thought about depression and they actually asked me to fill a prescription for him for depression medication. And I went to the pharmacy that day and filled it and cried all the way home and said, I know that's not it. I kept asking about Lyme. Could it be Lyme? No, he said, it doesn't present this way according to the Lyme guidelines I know. I heard that again and again and again. And as other people here have testified, it's quite frustrating when you're looking at the eyes of your child, who thinks that they might be dying and knowing that you may not be doing everything you can.

Finally, a doctor in New Hampshire diagnosed him but he said because he was so sick, he was probably going to need long term antibiotics and he was not willing to do so. I asked him, where can I go? And he suggested Dr. McNeil, who was considered one of the few Lyme specialists in our state. Who was in the midst of closing his practice at that time, in part because of the subtle or not so subtle pressure of the community, medical community. What other options did I have? I was told to drive to Connecticut, like so many people out of state.

I drove to Connecticut. In short, I found an incredible doctor who has seen more than 10,000 pediatric Lyme cases. He supports the ILADS guidelines. He treats freely because he's 80 years old, he has nothing to lose. His kids are grown, he's not worried about losing his house. He treats because he's passionate about making people better. He put Tucker on two years of aggressive antibiotics, two years. No side effects, no infections. If Tucker gets strep today, he responds to antibiotics and gets better, okay? The treatment saved Tucker's life.

There are few of those doctors in New Hampshire, as you've heard. I talked to some of them the last few days. You might notice that most of them aren't here, besides Dr. Young and a few others. One of them called me yesterday and told me she planned to call the members of this committee individually in the next couple of days. She didn't want to have her name released in public or face the scrutiny from the Medical Board members at this hearing.

Another doctor called recently to thank me for working on this committee and said she would definitely treat with ILADS guidelines if this legislation passed. Another told me that because of the unknown and I quote risk to my practice, I will only treat my own long term patients for chronic Lyme, even though I get calls every day from long term, from patients of other doctors. Without this legislation, she said, there's no incentive for physicians to become more educated about other guidelines. They need protection to stick their necks out.

I'm not asking you today to decide which standard of care is correct. You've heard that over and over. New Hampshire patients just need to hear all sides of the Lyme argument. We need to know that we have options. We need to know that our doctors will be able to treat freely based on an individualized clinical diagnosis and evaluation, not based on serology, test results or whether I have a bull's eye rash or not.

I asked Tucker last night what the most important message he wanted me to make to your committee was. And he said simply, tell them I am healthy thanks to a doctor in Connecticut that was willing to stick his neck out every day.

So I'm here asking you, asking you to protect the rights of New Hampshire's doctors who treat Lyme disease based on individualized clinical evaluation. I think that this legislation will help create a safer environment. More people will get treated and people will not go on to become chronic.

Thank you. I hope you take the time to review the facts from both sides represented here and I hope you do the right thing. **See written testimony of Julie Hall attached hereto and hereafter referred to as Attachment 14.**

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions? Okay, seeing none. Barbara Flocci?

Ms. Flocco: Flocco.

Senator Jacalyn L. Cilley, D. 6: Flocco. And next James Flower?

Mr. James Flocco: Flocco.

Senator Jacalyn L. Cilley, D. 6: Do you want to come up together? We are really, I'm afraid that there are going to be people here in an empty room shortly.

Ms. Flocco: Sure, that would be fine. I'll get started right away. I don't have anything prepared and I'm not much of a speaker, but.

Senator Jacalyn L. Cilley, D. 6: All we want, I mean, as you probably have heard, we've heard the symptoms of the disease. We've heard the doctors are concerned about treating under an approach that is not recognized by IDSA. We've heard that the Department of Health and Human Services, as well as the Medical Society, follow the IDSA guidelines. So if that's what you want to confirm, that's fine. If there's anything that you can add to that, that would be helpful.

Ms. Flocco: I think I have just a few things to add.

Senator Jacalyn L. Cilley, D. 6: Okay.

Ms. Flocco: And I appreciate very much your consideration of this bill. Two years ago, our three year old granddaughter became very ill and had been very healthy up until that point. She found a tick on the back of her neck at the age of 3 and told us about it. I removed it. My daughter was a bit worried and I said I've never heard that there could be any repercussions as long as you remove it and everything should be fine. But then she started.

And she was taken by my daughter to the pediatrician in Rockingham County. She had the tick, she had the kid. He said she doesn't have a bull's eye rash so she should be fine, and removed the tick, refused treatment. This went on. A series of problems ensued. For a month she was in, she was calling and the guy continued to say we can test but not for awhile. The test won't show up any results unless we wait. And admittedly, the test is flawed.

So after waiting a month and seeing our granddaughter deteriorate quite rapidly, we were all getting very concerned. He finally, under pressure from us, did the test unwillingly. In the meanwhile, the results came back and he called back and said, no, it's a negative and can't do anything. I can't give her any treatment whatsoever under the present guidelines.

So my daughter was at that point so upset that we looked to Dartmouth Hitchcock, where we found a pediatric rheumatologist, who saw her, said that he believed that she had Lyme and that he prescribed two weeks of antibiotics and she would be fine. We took her home, she took those two weeks of antibiotics. Immediately, symptoms started to ameliorate and we saw improvement. But in the meanwhile, we were informing ourselves and starting to worry that that was not enough time on antibiotics.

We went back to him subsequently and said we were concerned about this, and he told us the following. He said you stop informing yourselves, you'll only worry yourselves. None of those things you're reading are true and two weeks is more than enough treatment, that's it. So we were dismissed. We waited several months. The granddaughter continued to deteriorate. We went, we could find no help statewide. We finally went to Connecticut but we had to wait several months for that. And she's now in the 14th month of antibiotic treatment and doing spectacularly well. So once again.

But in the meanwhile our daughter, who was sick for eight years, once again told it was this, that and the other. Because of our granddaughter, started to wonder. Went to this practitioner who does work here, was told you either have lupus, MS or Lyme. Tested for those three and now our son-in-law, it turns out he has it as well. They all have to go out of state for treatment, and it's quite expensive, not covered by insurance.

So I appreciate your considering this bill.

Mr. Flocco: I would urge this committee to solicit testimony, expert testimony, to determine whether the ILADS research is equivalent to the IDSA research. That's basically all I have to say.

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions for the Floccos? Thank you very much. I'd like to call Marilyn Rivera and then afterwards, looks like, is it Lauren Berry?

Ms. Lauren Lemay: Lemay.

Senator Jacalyn L. Cilley, D. 6: Could be. Lauren Lemay, of course, thank you. I apologize. I'm, you know, you'd think after 20 years of teaching I could read people's writing, but I have a hard time reading mine most of the time. So, Marilyn Rivera, welcome.

Ms. Marilyn Rivera: Yes, hi, thank you. I'm going to make it real brief.

Senator Jacalyn L. Cilley, D. 6: If you would state your name for the record.

Ms. Rivera: My name is Marilyn Rivera from Strafford, New Hampshire. I just wanted to say that I had Lyme years ago. And I wasn't tested and treated for it and I passed it on to my daughter, and so she now has the Lyme.

But I also just wanted to make a quick point. Someone said something about doctors are afraid to use the antibiotics because of the superbugs. My daughter was treated for over a year for acne with antibiotics, and it was never, it wasn't a problem. But when she was treated for Lyme disease, that became an issue.

And I also wanted to state that my doctor also stated to us that he, you know, it's just a matter of time before someone comes after him with disciplinary action for treating with long term antibiotics. And he said that, you know,

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that may happen but it's okay because he knows how many people, how many kids he has been able to get out of wheelchairs with the treatment. So even though it hasn't happened yet, it's definitely, you know, something that doctors are fearful about.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Ms. Rivera: Thank you.

Senator Jacalyn L. Cilley, D. 6: Are there questions? Thank you very much. So Lauren Lemay and following that, Amy Simoneau. Are you here?

Ms. Amy Simoneau: Yes.

Senator Jacalyn L. Cilley, D. 6: Yes.

Ms. Lemay: Good afternoon, my name is Lauren Lemay. I've been suffering from chronic Lyme disease since 2001. I took two and half years before I was diagnosed, had to seek treatment out of state, upstate New York. That for us was a little difficult, in fact monetarily and physically, to try to make those appointments in New York.

I currently see a doctor in New Hampshire. I need another stage of treatment of which he is very hesitant to do because of the possibilities of lawsuits. It just seems incredible to me to think that we have to go out of our state to get proper treatment for Lyme disease. When we look, recently in October I got bit again and I was in Concord Hospital having a tick removed. The doctor looked at it, said it was most likely a deer tick. I'll give you doxycycline. I asked to have the tick examined to find out if in fact it was a tick that was carrying Lyme disease, since 70 percent of the ticks in New Hampshire in this area carry Lyme. Never got the results of that test. Went back to my doctor, then had another prescription to antibiotics.

So the point that we now know, going into some of these systems, that doctors are just not knowledgeable about this disease and the effects of this disease. Thank you.

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions for Ms. Lemay? Okay, so if I could, if we could have Amy Simoneau, and following that, Kim Schillereff, are you here?

Ms. Kim Schillereff: Yes.

Senator Jacalyn L. Cilley, D. 6: Okay, thank you.

Ms. Simoneau: Hello, Madam Chairman and Committee members. My name is Amy Simoneau and before 2004 I was considered to be in great health. I went to a doctor for an annual physical for preventive reasons only. I was an avid rock climber, ice climber, mountaineer, hiker and ran my own business successfully.

But unfortunately my life changed as of the beginning of year 2004, the spring. My first diagnosis was a spider bite. With reoccurring sinus infections and mono like symptoms, my good health slowly deteriorated and my once a year doctor's visits averaged 22 visits per year for two years. My symptoms worsened as time went on, with severe fatigue, heart palpitations, vertigo, meningitis, Bell's palsy, memory loss, slurred speech, unexplained sweats and chills, severe joint pain, poor circulation which later brought on pulmonary emboli, hospitalization for two months, MRIs, CAT scans, x-rays, frequent ER visits. Need I say more?

I had over five doctors and numerous specialists clinically misdiagnose me. I had the Titer test done twice, with both results negative. I've been labeled with chronic fatigue syndrome, fibromyalgia, Meniere's disease, Sjogren's syndrome, lupus, TMJ, autoimmune deficiency and protein C deficiency. My life was altered during those years, with loss of unemployment (sic), being disabled, financial hardship, loss of friendships and depression. In late 2005, I was clinically diagnosed and tested using the Western Blot out of my own pocket, and found that I had chronic Lyme disease along with several co-infections. I have been on long term antibiotics for almost five years now. With long term antibiotics, I can actually say I have most of my life back. I owe my improved well being to my Lyme literate doctor. I owe it to him, who has more strength and commitment in helping patients achieve their optimal health and lifestyle, rather than listening to lobbyists and majority rules.

Ticks, pharmaceutical companies and insurance companies may pull the last penny I have out of my pocket, but I actually sit here before you in support of the bill, 1326, and ask each one of you to approve this bill and allow our doctors the freedom to choose the proper treatment that works for their patients. Thank you for your time. **See written testimony of Amy Simoneau attached hereto and hereafter referred to as Attachment 15.**

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions? Seeing none, I'd like to see Kim Schillereff, and following that, following her.

Senator Michael W. Downing, D. 22: Looks like McGuire.

Senator Jacalyn L. Cilley, D. 6: Is it Hollis McGuire?

Ms. Hollis McGuire: Yup, that's right.

Senator Jacalyn L. Cilley, D. 6: I'll be darned, okay.

Ms. Schillereff: Hi, my name's Kim Schillereff. I called every one of you on Thursday night, left messages on your machines. I also called 60 other Reps the night before that.

I have a doctor and I'm being treated, I've been treated since July. I was bit again in November, bit again in March and bit by a regular tick last week. I'm here for the people who I keep trying to tell, go see my doctor. And he keeps telling me to stop sending people, I'm going to lose my license. I said, I want to help others who are like me, who went undiagnosed, who don't know what to do. Who are out there saying, I've got pains, I was told I had lupus, I've got this, I've got that. I said you've got the rash, you've got the aches, you've got the tick bite. You have Lyme, not lupus. They won't, you know, people won't listen.

I just don't know what to do because I am here to try to help others. I will tell everybody I know about Lyme disease. Two of my neighbors came down with it this summer. They both got diagnosed immediately. One didn't have it, one had a positive test, the other was negative. She was 91, thought she was going to die, she couldn't get out of bed. Her son was 60 and went down for the count. A neighbor next to them has it. He's had it, like me for five or six years. Comes and goes, you have good days, bad days.

The first thing I had was psoriasis, which is, why would that be Lyme disease? That's autoimmune stuff. I didn't have any idea that's what it was. I went and saw under my skin and said, I think I have this. I went and got the Western Blot test, it says right on it, CDC negative, IGENEX positive. So I'm not even a reportable case in New Hampshire. It's crazy, I mean, so.... I just don't know what to do anymore but I would really like you to pass this bill so I can keep giving out my doctor's name without him saying please stop. **See written testimony of Kim Schillereff attached hereto and hereafter referred to as Attachment 16.**

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions? Okay, so we'll hear from Hollis McGuire next and then Erin Fallon after that. Is Erin here?

Ms. Erin Fallon: Yes.

Ms. McGuire: Good afternoon. My name is Hollis McGuire. I was diagnosed with Lyme disease in 2003, treated for 28 days antibiotics. The treatment wasn't adequate, the disease recurred. My doctor was very sympathetic but he wasn't knowledgeable. He just didn't know what to do.

It took me years to find a doctor who is Lyme literate. That doctor didn't just put me on antibiotics. He tested me thoroughly and I'm going to be tested all the way through my course of treatment. I contrast this with people who have to travel out of state for care. I don't think I could get such a close level of care and so much monitoring unless I had a doctor in New Hampshire.

I see this as an economic issue for the state of New Hampshire. The disease takes productive people out of the work force and it keeps them out of the work force. Coupling that with the highest rate of the disease per capita in the country and a state where most doctors are not Lyme literate, and that is not a good economic answer for this state.

So I ask, what is the economic cost to the state, with or without this bill's passage? I believe we need the bill to both increase the knowledge of our New Hampshire doctors and to keep our citizens healthy and productive. Thanks.

Senator Jacalyn L. Cilley, D. 6: Thank you. That was succinct. Any questions? Okay, thank you very much. Erin Fallon, followed by Arlene Stoppe.

Ms. Fallon: Good afternoon.

Senator Jacalyn L. Cilley, D. 6: Good afternoon.

Ms. Fallon: Thank you for your patience this afternoon. My name is Erin Fallon, I live in Strafford, New Hampshire. I'm married to Tony Fallon, whom you heard earlier today. We have three children, ages 27, 24 and 20. All three of our children were born with Lyme disease. They got it from me. I grew up in Connecticut, had multiple tick bites and bull's eye rashes.

I had a litany of symptoms growing up and continued undiagnosed for many years. My children also had a litany of symptoms, but since it's a relapsing and remitting disease, we kind of lived with it and really didn't know what to do with it. And went through the two-tiered approach that the IDSA suggested, would have inaccurate results. So you just, it was just one of those things. I ached, I lived with it. My kids ached, they lived with it. Doctors didn't know what to do for it.

For me, everything hit the wall about six years ago. I was in graduate school and working part time in a physical therapy practice, when suddenly I had a drastic loss of memory and developed severe seizures. At that time, I was in graduate school in Connecticut while living in New Hampshire, so I was referred to an ILADS doctor in Connecticut. He immediately put me on intravenous antibiotics and I began to recover. We treated for Lyme and for co-infections and I recovered more. Then I got worse, so I was referred to an ILADS neurologist, and found out that as a result of the untreated Lyme, I developed a rare degenerative neurological disease. Now I'm being treated weekly intravenously for that. We don't know when that will ever, will end.

Still, life goes on and I feel very blessed. My eldest daughter developed a severe sinus infection with body aches that wouldn't go away. At the time, she was living in Virginia, so I sent her to see an ILADS doctor. She tested positive for Lyme disease, did many months of oral antibiotics and she's been doing fine for a long time.

My younger daughter got re-infected with a new strain of Lyme while running cross country in high school. She went off to college on a running scholarship, developed severe hip pain, headaches and concentration problems. So I sent her to my ILADS doctor in Connecticut, that's where she was going to college. She did two years of oral antibiotics, and she's doing fine.

Our 20 year old son is still struggling. He's had relapses a couple times now, lost his ability to read at 15. Couldn't get an IEP in high school because Dr. Montero told the Special Ed director at the high school here in New Hampshire that chronic Lyme doesn't exist. Therefore my son didn't have a chronic infection and all his symptoms were all in his head. Well, yeah, they were in his head, but it was an infection in his head. So we had to pull him out of public school and send him to a private school. He's working really hard at Plymouth State. He testified at the House hearing but now with the extra tutoring he's getting at Plymouth, he decided not to come down today and asked me to speak for him. He'd really like to see this bill passed through the state so that he would not have to travel to Connecticut still to see a Lyme specialist who can really address his issues. **See written testimony of Erin Fallon attached hereto and hereafter referred to as Attachment 17.**

Senator Jacalyn L. Cilley, D. 6: Thank you.

Ms. Fallon: Thank you.

Senator Jacalyn L. Cilley, D. 6: Are there questions? Seeing none, thank you very much. So Arlene Stoppe and after that I have Greg Kettmann. I thought we heard ...?

Mr. Kettmann: Yes, I've already spoken.

Senator Jacalyn L. Cilley, D. 6: Oh, okay. I was going to say, I thought that name seemed familiar. So following Arlene, how about Whitney Williams. Are you here? Whitney Williams?

Ms. Whitney Williams: Yup.

Senator Jacalyn L. Cilley, D. 6: Okay.

Ms. Arlene Stoppe: My name's Arlene Stoppe. My story is similar to others, so I'm not going to bother reading through it.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Ms. Stoppe: I do want to make one point that I think is very important. The Medical Board would like you to believe that this legislation sets a dangerous precedent, and I put to you that they've already set a dangerous precedent by only having ILADS.

Senator Jacalyn L. Cilley, D. 6: IDSA's.

Ms. Stoppe: IDSA's information up on the websites, that's a dangerous precedent. And you can see all of the struggle with trying to get care over that one point. They've already set the precedent, we need to correct that. Would it be great for them to post both of them on the websites? Sure. When is that going to happen? Is that going to happen today? Tomorrow? Five years from now? Ten years from now? We can't wait, because this is a fatal disease if it's not treated. It's fatal. Thank you. **See written testimony of Arlene Stoppe attached hereto and hereafter referred to as Attachment 18.**

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions? Seeing none, I'll call upon Whitney Williams, followed by... Viki Williams, are you both with the same, do you want to come up together?

Ms. Viki Williams: Sure.

Senator Jacalyn L. Cilley, D. 6: Okay, that would be helpful as I think we still have something on the order of 15 speakers left and we are, I think we're going to have to close this down by 4:30, both because of the room. We all have, I've got to get, you know. Fine, so if you'd give your name for the record.

Ms. Whitney Williams: My name is Whitney Williams. I am 27, I live in Manchester, New Hampshire. I don't know if you want to state your name.

Ms. Viki Williams: Should I state mine now?

Senator Jacalyn L. Cilley, D. 6: Absolutely.

Ms. Viki Williams: My name is Viki Williams and I live in Greenfield, New Hampshire.

Ms. Whitney Williams: Over the years, I have been diagnosed with depression, anxiety, ADD, bipolar disorder and insomnia, TMJ, Meniere's disease, fibromyalgia, chronic fatigue syndrome, and many more. I believe I've had Lyme disease for 14 years, and I'm also being treated for Bartonella.

I just have a short statement to read, it's just one page.

Senator Jacalyn L. Cilley, D. 6: That would be helpful.

Ms. Whitney Williams: It is hard to write this. It is hard because my body aches and I am exhausted, and my neurological symptoms of chronic Lyme disease make words I have known my entire life an empty space in my mind. A hole where a word used to be. It is hard because even simple things are hard. Some days are very dark, some days are very lonely, some days are desperate and angry and hopeless. Some days I feel it all. I am angry to be 27 and missing out on my life. On days like today, I cannot spell my first name and I cannot hold a pen because my fingers hurt so badly and I cannot perform simple tasks related to my job. On days like today, I cannot keep track of what I am doing as I am doing it. On days like today, accomplishing anything meaningful is a rare accident. On days like today, the anger does not run out. Every day has become a day like today.

I feel that a crime has been committed against my life and my body. I feel my happiness, my health, all my potential as a human being has been held hostage with no ransom. I am a victim of the mediocre practice of medicine, a casualty of a for profit machine engineered to treat patients as casually as consumers at WalMart and I am one of millions. I have arrived at doctor office after doctor office, a typed list in hand and a sense of desperate hope despite the inevitable and persistent disappointments and dismissals. That hope was constructed of what I knew was at a cellular level. Something was wrong with me and I was wasting my life submitting to this nameless captor. I knew this with every step I have taken on this earth. With every pill I uselessly popped, with every night I wept myself to sleep, with every breath. I knew, I didn't just believe, I knew.

What I don't know is how my heart still manages to break so sharply, why it aches so freshly with this repeated and deafening loss. What I don't know is if the grief for what I have lost will ever run out.

Despite my questions, despite my multitude of symptoms and vast history, no doctor until recently cared to consider what might cause such a poor quality of life. No one thought it was strange for someone so young to be so unhealthy, to be so thoroughly damaged in so many ways that they either thought I was lying or I didn't know that I was making it up. I pointed out the strangeness of my list. I acknowledged that I was a challenge. Eventually, my hope was beaten out of me. I stopped looking for answers. I stopped believing I would ever feel different.

I am humbled by this disease. He is magnificent, malicious and miraculously small but brilliant bugs are beating the shit out of me. There is no poetry here. There are no moments of grace, there are no words adequate. There is no heart big enough.

My current doctor is the first person to believe I should and could feel different. My current doctor is the first medical professional to make a real investment in me to practice the kind of medicine all the other doctors in my life seem to have forgotten, of which there are dozens. My current doctor is the first doctor who didn't recoil from the word Lyme disease and who did not bat an eyelash when I expressed my fears about what my health insurance might do if we tried to treat me with antibiotics for as long as it takes. My current doctor has a heart big enough to help heal me.

There is nothing more that I want (than) to (be) free of these bugs, nothing. All I ask of you today is that you help protect the choices I make about my health with the guidance of my physician. The supposed risks of long term antibiotic usage are my own and the reality is, there is no risk that I would not take to avoid living the rest of my life crippled and unable to spell my own name. **See written testimony of Whitney Williams attached hereto and hereafter referred to as Attachment 19.**

Senator Jacalyn L. Cilley, D. 6: Thank you. Viki Williams.

Ms. Viki Williams: I have a slightly different take on this situation, and I don't mean for this to be pedantic in any way. But I offer this, it's a very brief statement.

Our country was founded on an idea, an idea from the Enlightenment that all human beings are innately intelligent, capable of reason and are therefore qualified to self government. The Enlightenment philosophers also recognized the moral conflicts which make this so difficult.

I believe it is important to remember the simple founding principle as a guide post to one of the most difficult and challenging conditions of governance that we the people and you the government face: the health, well being and subsequent right to life of all people. The Founders guaranteed us the right to make choices concerning our own health and well being. They could not, however, have imagined the current nexus of the medical, industrial, governmental complex that has fouled this simple moral premise. No where is this more pungent than within the Lyme paradigm.

I would like you to listen to this quote. After listening to the commencement address by Steve Jobs, I realized that the single most devastating thing about fighting chronic Lyme disease is not the endless consuming pain or the unfathomable fatigue or the loss of my mental faculties. No, it is the deafening roar all this creates that drowns out my dreams. The noise of this disease takes up so much space that there is no room for my heart to speak. That is the hardest part. This was written to me in a personal email on Saturday by my daughter.

Clearly, you as a body have a choice here when it comes, and with it comes a high degree of moral liability. Emmanuel Kant would caution you to make this decision in the light of the greater good, respecting the innate capacity of all human beings to make their own choices. Within the framework of our governance, I urge you to support HB 1326 and do the right thing. Thank you. **See written testimony of Viki Williams attached hereto and hereafter referred to as Attachment 20.**

Senator Jacalyn L. Cilley, D. 6: Okay, thank you. Are there questions? Thank you very much. Could we hear from Susan Patteson, and following that Laura Herd. Both in the room?

Ms. Susan Patteson: Yes.

Senator Jacalyn L. Cilley, D. 6: Okay.

Ms. Patteson: I'm not going to read all this.

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Senator Jacalyn L. Cilley, D. 6: Thank you. And if you would just try, again, not to, you know, to refrain from repeating what we've already heard because ...

Ms. Patteson: I will do that.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Ms. Patteson: My name is Susan Patteson from Strafford, New Hampshire. Eighteen of my friends and family members and my friends have Lyme disease. Almost all of us were either misdiagnosed or treated by the IDSA guidelines, unsuccessfully. I was treated five years ago by those guidelines. I thought I was fine. Doctors sent me on my way.

And within a year and a half, I developed neurological symptoms, arthritic symptoms. I too went to Dr. McNeil's practice, which was called the Seacoast Lyme Center, so that kind of waved a flag. Hi, I'm treating Lyme. He treated me for six months before he started to close his practice. I actually started to get better and had a lot of hope that I was going to get well. And at that time, he gave me a bunch of names. Many were out of state and because I'd made a lot of strides, he didn't think I would require IV antibiotics. He sent me to, he said you know, maybe this particular doctor could help you that's here in New Hampshire. So I went to that doctor and he did continue to treat me and I'm still being treated. That would make me on antibiotics for three years of antibiotics. I've never been on IV antibiotics.

I asked my doctor how he got into treating Lyme, the one that's treating me. And he said, I never wanted to treat Lyme disease. This is not what I set out to do but I kept having these patients come in with all these autoimmune things. And when I looked at them according to the ILADS guidelines and treatment criteria for diagnosing and that I tested them. Extensive testing, and I started treating them, they got well. And he went on to tell me, he said I'm being watched, I've been told I'm being watched by the Board of Medicine. I said why in your right mind would you treat people where if you feel you're under threat for losing your license? And he said, I cannot in good conscience as a doctor not treat people if I know I have an answer to help them get well. And that is what is happening in his practice. My doctor is not here today, he is not here today because he doesn't want his face shown.

He also went on to tell me specifically about IV antibiotics. He said I have so many patients that meet the criteria for this, but I am not willing to treat with IV antibiotics because I'm afraid that that will bring my practice under undue scrutiny and I will lose it altogether. So that's my story of my doctor.

I have a couple other answers to the question why should we offer statutory protection to doctors who wish to treat with long term antibiotics. Multiple people have testified here today that they went to Dartmouth Hitchcock and those doctors offer them no help. That is inexcusable. This is the premiere doctor, this hospital in our area. And not just in New Hampshire, people come from all over the country to go to Dartmouth. And they offer no help and no answers. Those patients went on to talk about having to go out of state and other places to get help.

The Board of Medicine gentleman who spoke representing the Board of Medicine today said, you know, we're not going to discipline. We don't want to discipline people for this sort of treatment. And I would like to believe him, but his word in this hearing is not binding. What is binding is something that protects doctors to have the freedom to treat people like myself.

I went off my antibiotics in November and just working on this bill and adding an extra 10 to 20 hours into my week of work, my symptoms re-occurred, and so I've been put back on. My doctor has that freedom. I would like him to be able to treat freely.

The concern about Dr. Montero. Dr. Montero says we've got lots of people here with chronic illnesses. So many people are sick. Yet if we're only willing to put the IDSA guidelines on our website in New Hampshire, we're going to continue to have that same problem. When pushed, and I'm not sure if it was you, Chairman, or someone else. Pushing Dr. Montero, asking him, would you be willing to do this? He did not say yes, he did not say yes, that ILADS guidelines and criteria and the people that treat and the IDSA people, they are totally coming from different world views. They are coming from different world views when it comes to their medicine and they cannot reconcile. So we need to protect our doctors to treat patients.

I ask you today, what are the people in Rhode Island, California, New York and Connecticut, where this bill passed unanimously in the Senate and in the House. What do they know that we don't know? Why are they willing to do this? This bill is based on the Connecticut bill, so why would it pass there? Why aren't we willing to do that? And New Hampshire unfortunately is number one in the country for Lyme, and I think we should be number one in being willing to put the people of New Hampshire, help them out.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Ms. Patteson: Thank you.

Senator Jacalyn L. Cilley, D. 6: Are there questions? Okay, Laura Herd and following Laura, Douglas Newton. Are you here?

Mr. Douglas Newton: Yes.

Senator Jacalyn L. Cilley, D. 6: Okay.

Ms. Laura Herd: Hi, my name is Laura Herd.

Senator Jacalyn L. Cilley, D. 6: Hi.

Ms. Herd: Thank you for your patience, for listening to us. I just have a couple of points. I've been diagnosed for 15 months. I come across a lot of people who have this illness and some of them have been denied payment by their insurance companies. The reason has been that chronic Lyme disease does not exist based on the IDSA guidelines. I am a 34 year old otherwise healthy woman, and I was denied life insurance based on chronic Lyme disease. So double standard.

I also wanted to point out that I am seeing a Lyme literate doctor, I drive to New York State for this. I do so under great expense because he's an out of network doctor. I also do this because he's one of the best doctors in the country and he is in a state where he's protected by a law such as the one that we're looking to have passed here.

I had to find another PCP because my PCP for years, I thought we got along so well, decided that she was no longer comfortable treating me. So I had to find a new one. This new PCP is in full support of my treatment. She works with my Lyme literate doctor. She told me just a couple of weeks ago that she was working with a Lyme patient who had chronic Lyme disease. She put the person on 28 days of IV therapy. The person got 60 percent better, so she decided I'm going to do a second month. When she called it into the pharmacy, the pharmacist said that that was out of the IDSA guidelines and he refused to fill it and he reported her to her employer. So now she is working in fear at her job. She's not in fear that the Medical Board's going to come down on her, but there's no incentive for doctors to treat patients with chronic Lyme disease because the pharmacists and the people looking after them who are, want to damage their career.

So I just wanted to point out those few points. And I truly thank you for sitting here for so long and I hope that you will vote in favor of House Bill 1326. **See written testimony of Laura Herd attached hereto and hereafter referred to as Attachment 21.**

Senator Jacalyn L. Cilley, D. 6: Thank you. Before you leave, Ms. Herd, could you provide evidence to the committee of being turned down for life insurance because of chronic Lyme disease?

Ms. Herd: Absolutely. I absolutely can, I can mail that to you.

Senator Jacalyn L. Cilley, D. 6: Would you please?

Ms. Herd: Sure, absolutely.

Senator Jacalyn L. Cilley, D. 6: Thank you and expeditiously if possible, we're going to have to exec this bill by next week.

Ms. Herd: I can mail it tomorrow.

Senator Jacalyn L. Cilley, D. 6: Great, thank you.

Ms. Herd: I can actually drop it off tomorrow.

Senator Jacalyn L. Cilley, D. 6: Wonderful, thank you. So Mr. Newton, and then followed by Laura Schwartz.

Mr. Newton: My name is Doug Newton, I'm from Warner. I'll try to give you bullet points.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Mr. Newton: I have Lyme disease. I was diagnosed last October, but I've had it for a lot longer than that. My, I've got kind of a mild case, I don't have any aches or pains, I just have what's called encephalopathy, which is a brain infection. And the symptoms are extreme fatigue and I don't know, confusion or just extreme attention deficit. But those two symptoms together made it so that last fall I couldn't work. I couldn't really do anything. If you gave me a list of things to do while I sat at home feeling bad, I couldn't get any of them done. And at the end of the day I couldn't tell you why I hadn't got them done. Encephalopathy.

So last October I was diagnosed and the day of my first appointment with my doctor was pretty amazing, because I saw fear in his eyes when he diagnosed me. He just, I was one more liability for him that he was taking on that, partly because my encephalopathy is not considered by the CDC as a major symptom, and so not diagnostic. And so with just the test and the encephalopathy, I was kind of, I don't if I'd count as a CDC probable. I hope I would.

He told me, he said, Doug, I prescribe antibiotics to a 15 year old girl with acne, it's not a problem. But if I prescribe the same antibiotics to that same girl for Lyme, someone is looking over my shoulder and is apt to ask me why I'm doing that. And thinking about it today, the question is, who is looking over his shoulder? And we've heard from the Medical Board that it's not them and that they are not ... But the obvious answer is, my insurance company. Insurance companies are looking over all doctors' shoulders and in the history of Lyme, they've questioned the cost and the prescription of long term antibiotics. And my question would be, why are insurance companies practicing medicine? Because that's what it feels like is happening here and they're looking over the doctor's shoulder and that they're also, they're also intimately involved in the decisions that hospitals make and the doctors make as they dispense medicine.

Then I'd like to thank you, Madame Chairman, for having done your homework on this. You've obviously read a good deal.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Mr. Newton: The highlights, I've read a lot about it also, and the highlights that I would like to give you. One is animal studies. Dr. Montero said today that ...

Senator Jacalyn L. Cilley, D. 6: But because of the time constraints, Mr. Newton, and we're again about to lose a few more members here. So the animal studies are not relevant to, you know, to this bill.

Mr. Newton: The only point is that in all the studies in a lot of different animals. You can dissect an animal after the end of the study when they've infected animals and treated them. No matter how hard you treat the animals, there are still live bacteria in the animals at autopsy. That's my only point, is that.

Senator Jacalyn L. Cilley, D. 6: Okay.

Mr. Newton: And it's been mentioned that there are lots of studies that show all the ways that Lyme can hide from the immune system and can resist antibiotics.

And the point hasn't really been made here today that the, although I hope you're aware of it, that the Connecticut Attorney General's feeling was that the panel of 16 doctors of the IDSA ...

Senator Jacalyn L. Cilley, D. 6: Have been co-opted and may have conflicts of interest, that's correct.

Mr. Newton: Was corrupt, yes.

Senator Jacalyn L. Cilley, D. 6: I don't know that he used the word corrupt, but ...

Mr. Newton: One other person, one last thing. One other person said that this is an economic disease, and I think if you read the book *Cure Unknown*. It is an economic disease in the sense that the author of that book, she and her husband and both kids had Lyme in New York state in the middle of the epidemic. And she said that because of doctors fearing to treat Lyme, if you were wealthy and you were well connected, you could probably find a doctor who would treat you and you could get the treatment you needed. And that a lot of other people didn't get that treatment.

Thank you for listening to us today.

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions? Okay, I'd like to see Laura Schwartz and followed by Cherylann Victor. Cherylann Victor? You're Cherylann Victor?

Ms. Cherylann Victor: Yes.

Senator Jacalyn L. Cilley, D. 6: Okay, is Laura Schwartz here? Laura Schwartz is not here, if you'll come up Cherylann. Followed by ... Tony Fallon, we've already heard from you. Alright, you were down a couple of times here. You don't get points for putting yourself down two or three times. So followed by Kary Jencks. Kary Jencks still here? Okay, not here. Followed by Pamela Broll. Pamela?

Ms. Pamela Brown: Brown.

Senator Jacalyn L. Cilley, D. 6: Brown, sorry. So followed by Pamela Brown. Then we'll get to the Reps and we should be ending in the next 15 minutes if we're succinct.

Ms. Victor: Hi.

<u>Senator Jacalyn L. Cilley, D. 6</u>: Hi.

<u>Ms. Victor</u>: My name is Cherylann Victor, I live in Londonderry. My history is that most likely I went undiagnosed with Lyme disease for 38 years. And I was finally diagnosed by a Lyme literate doctor a little over four years ago.

A couple of points that I want to make are that I was on six months of antibiotic therapy when I was first diagnosed and then it was a little after, a little over a year after those six months that I was put on a month of IV antibiotics. If I had, if the treatment had been stopped after a month, I can tell you that I still would not be functioning. Probably because I went undiagnosed for so many years, I am still not well, but I am a whole lot better than I was. And so the point I want to make is that there is such a thing as chronic Lyme disease and people keep talking about there are no studies that show that long term antibiotics work. Well, they should just study the people in this room, and I'm one of them. And they do work.

The other point that I wanted to make concerning chronic Lyme disease is that Laura was turned down for life insurance. I was turned down by every single insurance company that practices in New Hampshire for health insurance. I'm on Medicare right now. And when I went from COBRA to Medicare I had a period of five months or whatever, and I couldn't go without insurance. And I had to end up on the New Hampshire Health Plan, which covers uninsurable people, and I had to pay $777 a month premium. And so obviously, somebody believes that there's such a thing as chronic Lyme disease, because they won't even insure us.

And then one of the doctors had talked about the IDSA guidelines and he touted how they were based on government guidelines and he mentioned CDC. Well, the problem is that CDC guidelines were never meant for diagnosis. And they were meant for surveillance. And I think, by the way, just in the course of my journey, I was seen by an infectious disease specialist in New Hampshire and I had, to any lay person who looked at me, it would have been obvious that I had some sort of serious acute illness. I had swollen lymph glands out to here. I was spiking fevers every night for seven weeks, high fevers like up to 103, 104. I had shaking chills, soaking night sweats. And she never tested me for Lyme, the BC Bartonella, or anything else. Actually, no infectious disease, and she is part of IDSA.

And the final point that I really wanted to make is that I think just by the testimony you've heard from the people themselves, from the Department of Health, the Medical Board and the IDSA members, I think that should be proof enough of what we are up against as Lyme patients in this state. And it's a real battle. And I am asking you all to please vote in favor of House Bill 1326 and to please recommend that the Senate also votes in favor of it.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Ms. Victor: Thank you.

Senator Jacalyn L. Cilley, D. 6: Are there questions? Pamela Brown. And then I think we can go on to our Reps. Is Representative Perry here? There you are. So we're going to go... Let me ask, just before you start, Ms. Brown. Are there any other members of the public who thought they were on these lists, prepared to testify, that have not been called?

Dr. Lewis Rosenthall: I'd like a minute. I'm a member of the public, I'm not on the list.

Senator Jacalyn L. Cilley, D. 6: You're not on the list and you didn't sign in?

Dr. Rosenthall: No, I signed in over in, but I didn't sign in for this, to offer ...

Senator Jacalyn L. Cilley, D. 6: You didn't sign in for what?

Dr. Rosenthall: To speak.

Senator Jacalyn L. Cilley, D. 6: Oh, so are you on these lists? Your name is?

Dr. Lewis Rosenthall: Lewis Rosenthall.

Senator Jacalyn L. Cilley, D. 6: Lewis Rosenthall.

Dr. Rosenthall: If I could have a minute.

Senator Jacalyn L. Cilley, D. 6: Alright. Well, as you know, I've been saying several times that we're running out of time, so we had another whole ... Except for Mr. Rosenthall, so after Mr. Rosenthall, what I'd like is to ... And you're welcome to come up together, following him, Representative Perry, Representative Cebrowski, Representative Chase and Representative Schmidt. I saw him, did he just ...?

Senator Sharon M. Carson, D. 14: Madam Chair? Excuse me, I think there was another member of the public who wanted to testify.

Senator Jacalyn L. Cilley, D. 6: And your name is?

Ms. Pam Veiga: Senator Cilley, Pam Veiga.

Senator Jacalyn L. Cilley, D. 6: Pam Veiga. Are you ...

Ms. Veiga: I just had a quick question. I'm on the list but I did not check off whether I was speaking or not. I just have a simple question, it's about the language here, and I don't know if that's appropriate or not here in this setting. As far as expanding it to more than just the doctors.

Senator Jacalyn L. Cilley, D. 6: So what you're hoping to do is propose some additional language to the bill, okay? So that's different than asking. Typically, the public doesn't ask questions, they testify and we ask questions. Okay. So we have Mr. Rosenthall and Ms. Veiga. And we have, now I've lost your name. Pamela Brown, right?

Ms. Brown: Right, yes.

Senator Jacalyn L. Cilley, D. 6: Great. Nice to see you again.

Ms. Brown: Thank you. Good afternoon. My name is Pamela Brown, I live in Nashua, New Hampshire. I previously worked as a Principal QA engineer and have an MBA. I'm currently disabled with serious cognitive, physical and emotional problems. And I believe that this is in part due to undiagnosed Lyme disease. My symptoms first appeared in 2002 but remained undiagnosed. In 2008, after a friend urged me to be tested, I tested, was negative with the Titer yet positive with the Western Blot. And although I had a list of 30 Lyme symptoms and the positive Western Blot disease (sic) in my hand, my primary care physician said that quote unquote, this doesn't necessarily mean that you have Lyme disease. And he in fact refused to diagnose me with Lyme because it was controversial.

I've had to go out of state to be treated by a Lyme literate doctor and the treatment has included long term antibiotics. I travel four and half hours round trip every six weeks. I also tested positive for lubyziosis and ehrlichiosis, two common Lyme co-infections. Lyme, lubyziosis and ehrlichiosis are all potentially fatal and if left untreated, if left untreated. And I believe that my Lyme literate doctor has literally saved my life.

I urge you to support House Bill 1326.

Senator Jacalyn L. Cilley, D. 6: Thank you. Are there questions? Thank you very much, Ms. Brown. Pamela Veiga.

Ms. Veiga: Thank you for honoring a simple question. Pamela Veiga, Hollis, New Hampshire. I just have a question regarding the bill, Lyme disease under section 2. Lyme disease means the clinical diagnosis by a licensed physician. Could you expand that at this point to include nurse practitioners?

Senator Jacalyn L. Cilley, D. 6: Only if somebody proposed that amendment and the committee accepted it.

Ms. Veiga: Would that proposal come from the audience?

Senator Jacalyn L. Cilley, D. 6: No, that proposal would have to come from a legislator, so it's... One of the things you might want to do is to see the prime sponsor of the bill, see if he's willing to put forward an amendment. That would still have to be accepted by the Committee, and to be taken on as a Committee amendment. Typically what we do when we go from one body to the other with a bill from the other side, is that if that person.... When I left, I was bringing a bill, actually I was bringing a bill, an amendment to a Senate bill. But nonetheless, I proposed it but if the Committee accepts it, they accept it as a Committee amendment. But typically a legislator would put forward an amendment.

Gail, you'd know this better than I would. Just, well it's an interesting question. Has the public ever come in? I've seen our departments come in with proposed amendments and written language. Has the public ever done that?

Gail Brown, Senate Secretary: Not that I'm aware of. I think you're absolutely correct. The public can go to the prime sponsor of the bill and to their own legislator.

Senator Jacalyn L. Cilley, D. 6: Okay. That's what's wonderful about having somebody with great institutional memory. Okay.

Ms. Veiga: Okay, so the sponsor of the bill?

Senator Jacalyn L. Cilley, D. 6: I would check with the sponsor of the bill.

Ms. Veiga: Okay, thank you very much.

Senator Jacalyn L. Cilley, D. 6: Mr. Rosenthall. Thank you.

Ms. Veiga: Thank you.

Dr. Rosenthall: Thank you very much. I'm Lewis Rosenthall. I'm a member of the Board of Medicine. I've been practicing family practice in Concord for 34 years. I'd like to just remind you all of certain truths. We learn from our patients. It's been very interesting listening to all these Lyme patients and their ordeals.

Standards of care do, medicine may move slowly, but standards of care do evolve over time. Things are quite different here in Concord now compared to when I started in 1976. The Board of Medicine, you've heard the testimony of our President, my colleague Dr. Andelman. He is a respected man. And he's, as we all are, open in medicine for lifelong learning. I'd be interested of these, among the Lyme literate doctors who treat chronic Lyme, what their criteria are for IV versus PO and what length of time they do this for this patient versus that. And we're open to include that on our Board of Medicine website. So I, also on the Board of Medicine, we're a complaint driven organization. We don't, the only doctors that we are surveilling are people, are doctors that have already been disciplined for other things. We don't proactively look at methods of practice. So physicians in the state don't have to worry or be concerned about repercussions from the Board of Medicine.

I would urge you to oppose this bill because it certainly, there may be insurance coverage issues and that's another issue. But as far as doctors being in fear of prescribing long term antibiotics, there's precedent for this. It's been mentioned by others about long term antibiotics for patients with acne and other conditions, so there's precedent for that. I don't think that this bill is needed because of the way the Board of Medicine works and I do think it sets a bad precedent to legislate standards of care for conditions that will be evolving and continuing, hopefully, to evolve and change and improve. Because truly we're all patients, even though of us who are physicians.

Senator Jacalyn L. Cilley, D. 6: Thank you, Dr. Rosenthall, for coming forward. I have, and I don't know if you were here earlier. I have concerns. I have frankly some concerns about unintended consequences of this legislation. But that aside I, being a student of history and being interested in the medical field, you know, my perspective is that the medical field has been very, very... And this is not the right venue to be, but I have a question in this. But very slow to respond to innovation, often wedded to tradition, even when that tradition has been proven repeatedly not to work. And there's plenty of evidence of that.

But it brings me to a question that was raised earlier, about somehow IDSA has the, and I think it was Dr. Montero who gave this testimony. IDSA supports or bases its guidelines on double blind tests, on more credible research. Do you know the difference between ILADS and IDSA, and if so, you know, whether there's a credibility problem? Because some of the other things that were put forward by IDSA. When I was on their website this weekend, it seems to me that it was their website (that led) to one called Quackery. And Quackery said there's essentially no such thing as chronic Lyme disease and certainly it's bogus to be using long term antibiotics. I'm just wondering about these two approaches, promoted by two separate groups?

Dr. Rosenthall: I'm not, I'm a family physician. I don't know the relative merits of one group versus the other. But I can tell you that when I came to Concord in 1976, we had no endoscopy, we had no CAT scans, we had no MRIs, we had no heart program, no radiation therapy program. And the drugs that we're using now to treat many conditions hadn't even been invented. The statins, the SSRIs, so things do, the electronic medical record, which was adopted by my group in 2002. And since then, the applications have been phenomenal. And with the health reform bill passed in Congress, there's going to be incentives for more and more doctors to adopt that. So, and that would hopefully disseminate information better to all involved parties going forward.

Change, without change, we stagnate, so change is good. We have to be open to change and open to learn. But passing this bill is not going to protect doctors from the Board of Medicine. I can assure you, as a member of the Board, that that is not the case. And we are, both the public members and my licensed colleagues, are open to learn and to evolve and change, and to incorporate that on our website. And my hope is that the Board will be more visible to the public and to the State going forward than it may have been in the past. I've been appalled by some of these comments that have been made, we fear the Board's going to come down on us. The only way the Board investigates anything is if someone complains to the Board. Usually a patient.

Senator Jacalyn L. Cilley, D. 6: Senator Downing.

Senator Michael W. Downing, D. 22: Thank you, Madam Chair. That brings up another issue. If you receive a complaint from a pharmacy that the doctor is prescribing these long term antibiotics, is the Board going to follow that up?

Dr. Rosenthall: The Board will follow up a complaint from a reputable source, but if that complaint is based on standards of care which is subject to scrutiny, then it'll be dealt with appropriately.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Dr. Rosenthall: Thank you both very much.

Senator Jacalyn L. Cilley, D. 6: Could you start with, we've got the line up, right, Reps? I need to step out for a moment, but I'm now at a point where my husband's going to have to take the dogs to the vet. I'll be right back.

Senator Michael W. Downing, D. 22: Who do you want first?

Senator Jacalyn L. Cilley, D. 6: I think it's, is it Representative Perry?

Senator Michael W. Downing, D. 22: Representative Perry.

Senator Jacalyn L. Cilley, D. 6: Right down here, and then... Representative Perry.

Representative Robert Perry: Thank you very much. I will brief. There's a distinct disadvantage to appearing this late in the hearing, as things, most things get covered. But I would like to bring, I'm sorry, my name is Bob Perry and I represent the residents of District 3, Strafford County.

I would bring your attention to line 5 of the amendment. A physician licensed under this chapter may prescribe, administer or dispense long term antibiotic therapy, etc. So the language is enabling. There is nothing in this amendment that is obligatory or mandates in any way. So we are not asking you to support a bill that legislates one approach to Lyme disease over another. Or to legislate a new standard of care, or to legislate an exception to medically based care and treatment. We are asking you to allow New Hampshire doctors evidence based options for treating chronic Lyme disease, subject to individualized clinical evaluation consistent with one of the two federally recognized approaches to long term care.

On a personal level, I removed 30 ticks from my skin and clothing during the summer of 2009. And I've already begun taking ticks off myself and the dog. One I removed, I spent the night with a tick and it was attached to my scalp. Another one a few days later was headed for my arm pit. So the point is that we are all vulnerable to ticks and their bites, whether inside or outside the home, whether country or city dwellers. When we become the unwitting recipient of their bite and infection, we must know that the full measure of medical options for our recovery is available to us. And HB 1326 would go a long way towards that end.

So this bill is not about mandates. It's about compassion for those currently suffering with the disease and for those who will become victims of chronic Lyme disease and for those who will become victims of chronic Lyme disease into the foreseeable future. It's about allowing doctors to practice their professions in a manner consistent with the history of successful outcomes. It's about preservation of the sanctity of the doctor/patient relationship.

Thank you. **See written testimony of Representative Perry attached hereto and hereafter referred to as Attachment 22.**

Senator Michael W. Downing, D. 22: Do you have any written testimony that you want to pass in? Thank you very much. Representative Cebrowski.

Representative Peter Schmidt: He has left for the day.

Representative Claudia Chase: Excuse me, I am here.

Senator Michael W. Downing, D. 22: Please step forward.

Representative Chase: For the record, I am not Representative Cebrowski, but I am pretending to be him. I have written testimony from him, but he asked me to read the last two paragraphs, which are very brief.

Senator Michael W. Downing, D. 22: Could you just identify yourself for the record.

Representative Chase: Okay, I am sorry. I am Representative Claudia Chase.

Senator Michael W. Downing, D. 22: Thank you.

Representative Chase: The two paragraphs he asked me to read are: I did a little research and spoke to Connecticut Assistant Attorney General Thomas Ryan. He told me that their office had received a complaint from a group of citizens some time ago based on this conflict. After study, the AG's office felt an anti-trust approach was best and an investigation of the Infectious Disease Society of America and its Lyme disease guideline panel was launched. Attorney General Richard Blumenthal found that his anti-trust investigation uncovered serious flaws. Blumenthal said that "The IDSA's Lyme disease guideline panel undercuts credibility, allowing individuals with financial interests in drug companies, Lyme disease diagnostic tests, patents and consulting arrangements with insurance companies to exclude divergent medical evidence and opinion." He added, "The IDSA process was manipulated. We can't prosecute freedom to treat, doctors have the freedom to treat as they see fit."

I'm not going to read the last one, because you're the only person here and you can read that for yourself. **See written testimony of Representative John Cebrowski attached hereto and hereafter referred to as Attachment 23.**

Senator Michael W. Downing, D. 22: Thank you.

Representative Chase: I am no longer Representative Cebrowski.

Senator Michael W. Downing, D. 22: Did you wish to speak yourself?

Representative Chase: Now I have to come back again as myself. Can I, for the last second, can I just wait for the Chair? Mine is really brief. Can I grab her?

Senator Michael W. Downing, D. 22: You can try.

Representative Chase: You just missed my impersonation as Representative Cebrowski.

Senator Jacalyn L. Cilley, D. 6: I'm sorry.

Representative Chase: For the record, I am now Representative Claudia Chase. And it's kind of ironic that I was standing in for Representative Cebrowski, because I very briefly want to tell you what happened in the House.

On, whenever it was, the 17th, February 17th. Two rather right wing Republicans and two rather left leaning Democrats got together in support of this bill, because we knew it was the right thing to do. For me, for the first time in six years, I had a magical experience of working with Republicans this hard on a bill. And they felt the same about us.

Senator Jacalyn L. Cilley, D. 6: Representative Chase.

Representative Chase: It was magical.

Senator Jacalyn L. Cilley, D. 6: It is not germane to this bill to talk about, you know.

Representative Chase: Okay, so let me back up. But anyhow, what happened was, the Committee had voted interim study on this bill. And we had that killed in a division vote on the floor. And then six out of seven Representatives voted ought to pass on this bill. I think that is germane, very important.

Senator Jacalyn L. Cilley, D. 6: Yes.

Representative Chase: The reason I believe that happened was, as we spoke, as they looked up into the balcony and saw literally hundreds of Lyme patients, they realized that they were married to someone who had Lyme, they had a friend who had Lyme, we had a dog who had Lyme. They knew someone who knew someone who had Lyme. I mean, we're 400 members, we're pretty much a large part of the population in the state of New Hampshire. But they realized the connection. The people who didn't vote for it were a lot of the chairs and vice chairs, who felt they couldn't. But I felt that was a magical moment.

And I just want to make a couple of statements. We talked about precedent for laws for legislation for diseases. Breast cancer is a good one. There have been hundreds of bills passed in our states protecting it, breast cancer bills. The first one would be, the protocol for breast cancer used to be radical mastectomy. They put you out, they did a biopsy and then they chopped your breast off. And that was protocol. Seventeen states passed a law in the '70s allowing for alternative therapies for breast cancer. Okay, this seems a similar thing. Fifty states passed bills for breast cancer screening and the list goes on. There were literally several hundred bills passed, legislation passed.

And the only other comment I want to make is that in terms of conflict of interest and the IDSA guidelines. Three of the members of IDSA held patents to 22 of the DNA of the bacterium for Lyme, caused Lyme. There are two other people who are very closely associated with them who literally hold 103 patents, and then there are pages and pages of universities and other special interests who own hundreds of patents to the DNA for Lyme disease. So my opinion is that they're waiting to produce a vaccine (inaudible).

Senator Jacalyn L. Cilley, D. 6: Thank you. Representative Schmidt and then we have one more speaker who's asked for just a minute at the end of this and then we're shutting it down. We need to leave.

Representative Peter Schmidt: Thank you, Madam Chair, members of the Committee. For the record, my name is Peter Schmidt, I represent Dover

Wards 1 and 2. And I come before you today in strong support of this House bill. And the case has been made on both sides of the issue, so I don't wish to get into the specifics.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Representative Schmidt: I'm sure you feel the same way. And you've alluded to cases that you've investigated where the practice of medicine has made errors and been slow to recognize the reality of the extremely complex machine that we all inhabit.

And I recently, within the last year, had the doctors open me up, stop my heart, disconnect it, patch it up and so forth and so on. And put me, and here I am still among us. So medicine certainly has achieved great miracles, but it hasn't always been, as you know, a straight path. A long, many decades have passed since the days of Semmelweis when he discovered that, you know, it wasn't a good idea for people who had just been carving up cadavers to come in and examine newborn babies and their mothers. Causing childbed fever, which killed a lot of people in central Europe in those days.

But there still are things that medicine hasn't got right. And I believe that in general, the practice of medicine has not done right by the citizens of this country with regard to Lyme disease. And I don't think that this bill goes where the Medical Society and the Board of Medicine think it does. I don't, perhaps it sets a precedent but I don't think it's a dangerous precedent. I think we have to give, because the people who have appeared before you today and who appeared in even larger numbers before the House, these are not people who are imagining that they're seeing, you know, some religious figure in a knotty pine or a puddle of water. These are people who have had real experiences and they've had terrible experiences in many cases.

And I think we have to do everything we can not to benefit the practice of medicine at the expense of the people of New Hampshire. But rather to work hand in hand with doctors who are open minded. And I think we've seen some examples here today of some resistance to the idea of ... We've heard them say, no such thing as chronic Lyme. I really think we have to, I think we have to go in the direction of giving the people, you know, the support they need and the medical profession the support they need to the degree that, you know, you've got a fire extinguisher hanging on the wall that never gets used, not a problem. If the Board of Medicine is never going to prosecute or disbar (sic) somebody for doing this, then the fact that they are legally prohibited from doing so by this bill, not a problem.

<u>Senator Jacalyn L. Cilley, D. 6</u>: Thank you.

<u>Representative Schmidt</u>: I really think this is the way to go and I hope you will be as open minded as you've shown yourselves already. So thank you very much.

<u>Senator Jacalyn L. Cilley, D. 6</u>: Thank you. And I'd like to call on?

<u>Ms. Georgina Messer</u>: Georgina Messer.

<u>Senator Jacalyn L. Cilley, D. 6</u>: Okay, if you'd come and identify yourself for the record. And Georgina will definitely be the last speaker, because we're out of time.

<u>Ms. Messer</u>: Thank you, Madam Chair, for allowing me this opportunity. My name is Georgina Susan Messer and I have lived in Merrimack for about 25 years. The point I wanted to make. I have suffered with Lyme for many, many years, and have had to see an out of state physician, 14 hours drive. This physician is an internationally recognized infectious disease specialist, who began his career in HIV AIDS 20 plus years ago. He probably diagnosed the first case in North Carolina of HIV AIDS. Patients such as those you have heard before you today began presenting themselves on his doorstep and he was like, what do you have? He is no longer treating HIV AIDS. His practice is solely treating Lyme, very seriously ill Lyme patients.

What my physician has been through is what every doctor in New Hampshire wants to avoid. He was brought before the Medical Board because he was sued by Blue Cross/Blue Shield for prescribing unauthorized treatment, i.e., long term IV antibiotics for patients that, it's the guidelines, you know, standards of care did not help. He is not a doctor that would give up on his patients. He had a wealth of experience with infectious disease under his belt.

So we, I feel, are guinea pigs because there is no standard of care yet. They are still figuring it out and all we are asking by supporting this bill, is that we be allowed to decide with our physician what is best for us.

And there was one other point I wanted to make. Yes, Dr. Montero, many patients here told you their doctors had told them they're afraid. And I've heard that from friends who are seeing physicians here. My doctor refused to see me when I went back to her after I was back in my wheelchair because she refused to prescribe more antibiotics for me. What, do you want me to risk losing my license? It has a power that is putting doctors in fear because of politics. And ILADS is another set of guidelines that has been offered up by doctors who are treating chronically ill Lyme patients.

Senator Jacalyn L. Cilley, D. 6: And we heard that during the rest of the testimony, Ms. Messer.

Ms. Messer: Okay.

Senator Jacalyn L. Cilley, D. 6: So is there anything new that you would like to add?

Ms. Messer: So allow us please to have that as an option for our care, and House Bill 1326 would give doctors that ability.

Senator Jacalyn L. Cilley, D. 6: Thank you.

Ms. Messer: Thank you.

Senator Jacalyn L. Cilley, D. 6: Are there questions? Seeing none, I'm going to close the hearing on HB 1326.

Hearing concluded at 4:55 p.m.

Respectfully submitted,

Catherine S. Mullen
Senate Secretary
5/11/10

23 Attachments

Attachment 2

Thank you, Madame Chair. For the record my name is Gary Daniels. I am a Representative for Hillsborough District 6, representing the towns of Amherst and Milford. I am also the prime sponsor of HB1326 and speak today in support of the bill.

On January 28, over 200 people filed into the House public hearing on HB1326. They came not as Democrats or Republicans, conservatives or liberals, but as people united by one thing – their lives had directly or indirectly been affected or devastated by Lyme disease. They came seeking affirmation that their physicians have the right to diagnose clinically, and the assurance that their physicians have the freedom to treat their patients using the appropriate evidence based, peer reviewed guidelines that best fits the needs of those patients.

The testimonies of 36 people went on for over five hours. Three of them spoke against the bill. 115 people signed in supporting the bill, one opposed. In addition, 180 pages of written testimony from 85 people supporting this bill was submitted to the committee. You have also received a copy of that written testimony.

There are currently two federally recognized standards of care for the treatment of Lyme disease, though New Hampshire's Health and Human Services' website links to only one. The Infectious Disease Society of America (IDSA) states that chronic Lyme disease does not exist, that treatment for Lyme disease should not exceed 2-4 weeks and that people labeled as having chronic Lyme disease do not benefit from additional courses of antibiotics. The International Lyme and Associated Diseases Society (ILADS) asserts that Lyme disease can be chronic and can be successfully treated with long-term antibiotics by doctors who determine the duration of treatment based on *individualized* clinical evaluation. The viewpoints of both standards are reflected in peer reviewed "evidence-based" guidelines.

In spite of the fact that there are two recognized standards of care for treating Lyme disease, a charged political climate exists between these standards that has resulted in doctors around the country having their licenses revoked or suspended for no reason other than that they chose to treat patients with long-term antibiotics. I do not want that to happen in NH. It is not the intent of this bill to solve the differences between these standards - this for the medical community to resolve. It is the intent of this bill to allow doctors, based on a clinical diagnosis and their professional judgment, to treat their patients according to the standard they feel best suits the need of those patients, without the fear that their license will be revoked solely because they prescribed long-term antibiotics.

The heart of this bill can be summed up in the answer to two questions. We are being told there is no problem; that NH doctors can now treat at will. However, when asked if he would fear losing his license if he treated with long-term antibiotics, one doctor testifying against this legislation in the House stated that if he treated with long-term antibiotics on a regular basis, that someone would most likely take notice. Why would someone "take notice" if doctors were truly free to treat by either standard? This same doctor was also asked by a member of the committee: If someone wasn't successfully treated in 2-4 weeks, where were they to go? His response: "I don't know that I have an answer." In New Hampshire that is unacceptable.

It's unfortunate that Dr. Don McNeel, one of the state's few Lyme experts, could not be here today, as he is in South Carolina. He experienced the reality of the fears voiced by the aforementioned doctor. Dr. McNeel stated in testimony to the House that he closed his practice a few years ago, in part, because of pressure from the medical community for his successful treatment of hundreds of chronically ill Lyme patients using long-term antibiotics. His written testimony is the first in the packet of written testimonies you have received.

We have thousands of family members, friends, neighbors and constituents who are looking to us today for an answer. They have done their part by pushing aside their pain to show up for a hearing to plead for the passage of HB1326.

This bill does not legislate medical treatment, nor does it protect a doctor from medical board action if she or he were negligent or criminal in any way. We're not even asking you to spend money. We're simply saying that with two federally recognized standards of care for treating Lyme disease, doctors should be free to choose, based on a clinical diagnosis and their medical expertise, which standard of care best fits the need of their patients, without the fear of losing their license <u>solely</u> because they prescribed long-term antibiotics. When NH Lyme patients are denied access to all treatment options for no reason other than their doctors are afraid of repercussions if they treat with long-term antibiotics, there is something wrong, and it not only requires, but demands legislative action to restore the patient-doctor relationship.

HB1326 has the same language the Connecticut legislature passed unanimously. On February 17th the NH House passed this bill 300-56. We have the opportunity to provide some relief to those Lyme victims who have suffered far too long without in-state access to the care they need, and so I respectfully ask that you too support the passage of HB1326.

Thank you, Madame Chair.

Attachment 2

STATE OF NEW HAMPSHIRE
EXECUTIVE COUNCIL
STATE HOUSE ROOM 207
CONCORD, NEW HAMPSHIRE 03301
(603) 271-3632 FAX: 271-3633

JOHN H. LYNCH, GOVERNOR

EXECUTIVE COUNCILORS:
RAYMOND S. BURTON
JOHN D. SHEA
BEVERLY A. HOLLINGWORTH
RAYMOND J. WIECZOREK
DEBORA B. PIGNATELLI

April 26, 2010

Senate Executive Department and Administration
Senate Hearing
Legislative Office Building

RE: House Bill 1326 on Lyme

Dear Members of the Senate Executive Department and Administration:

The Executive Council held two public hearings today that prohibited us from speaking before your committee on the issue of antibiotic use that will give doctors the freedom to treat Lyme patients without fear of retribution.

We both support the passage HB 1326. With the passage of this bill the citizens of our state will be able to work with their physicians on a treatment plan that they feel is in their best interest without fear of retribution.

Sincerely,

Raymond S. Burton
Executive Councilor, District One

Beverly A. Hollingworth
Executive Councilor, District Three

DISTRICT ONE	DISTRICT TWO	DISTRICT THREE	DISTRICT FOUR	DISTRICT FIVE
RAYMOND S. BURTON 338 RIVER ROAD BATH, NH 03740 TELEPHONE 747-3662	JOHN D. SHEA 8 MCINTIRE ROAD NELSON, NH 03457 TELEPHONE 847-9008	BEVERLY A. HOLLINGWORTH 209 WINNACUNNET ROAD HAMPTON, NH 03842 TELEPHONE 926-4880	RAYMOND J. WIECZOREK 1060 RAY STREET MANCHESTER, NH 03104 TELEPHONE 624-1655	DEBORA B. PIGNATELLI 22 APPLETREE GREEN NASHUA, NH 03062 TELEPHONE 888-5245

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www.state.NH.US/council

Attachment 3

Plymouth Family Practice Center
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Presentation, New Hampshire Senate, 4/26/10

I am a family practitioner, practicing in Plymouth NH for the past 29 years. I am a member of ILADS. I am also the parent of a daughter with chronic lyme disease. I would like to explain why I feel your constituents need your protection.

First I am going to speak as a physician. I am not going to spend much time talking about lyme *treatment*. Despite the thrust of the bill, the argument about lyme *treatment* is actually an argument about lyme *diagnosis*. IDSA, the Infectious Disease Society of America, feels that long term antibiotics for lyme are not warranted—*because chronic lyme disease is a rare event that is extremely overdiagnosed.* In fact, the IDSA committee members who wrote the current national guidelines state openly in their guidelines: "late neurologic lyme disease is a very rare event. Collectively, only one patient over the past five years was diagnosed by panel members."

So why do so many people in this room think they have lyme disease? Fist, because there is an alternative national guideline for the diagnosis of chronic neurologic lyme disease. The physicians who diagnosed the people in this room follow the Burrascano guidelines endorsed by the International Lyme and Associated Disease Society, (ILADS). Second, because no one could come up with a better explanation for these people. Third, because the ILADS treatments work.

I am not going to get into the medical issues. I cannot summarize thousands of research and clinical articles that went into the ILADS criteria. This is a legislative issue because the medical community has difficulty allowing two competing guidelines. It became an issue for state government when IDSA labeled the alternative diagnosis rules as substandard care.

Substandard care is a legal term. Medicine is always defensive. Therefore many NH physicians skip ILADS criteria and automatically use IDSA rules just to avoid legal issues. Their concern is not specifically about lawsuits. IDSA has not been able to set a precedent in the courts that ILADS criteria are substandard. In other states, however, they were successful in threatening physicians' licenses if they prescribed according to ILADS guidelines.. This is having a chilling effect here in New Hampshire. The logical consequence is that patients do not have access to care if they want treatment for chronic lyme disease. That is why so many people came here today.

When I want a specialist's opinion for my chronic lyme patients, I send them south to Massachusetts, Connecticut, or NY to see board certified internists and infectious disease specialists. My patients are very willing to make the trip. That doesn't mean that they want to be restricted to out-of-state physicians, or the alternative--infectious disease specialists, rheumatologist, neurologists, psychiatrists who say "I cannot diagnose your problem—see someone else". After seeing five or ten specialists, they run out of people to ask! Ask the people here how many physicians they saw and how many treatments they tried before they found an answer that worked. Then ask if it was the ILADS criteria that worked.

Why do physicians in this state need the protection of this bill? Let me tell you a brief story.

My daughter went blind –briefly-- after an appendectomy in 1998, at the age of 15. Her blindness only lasted 15 minutes, but it recurred. Then she had unconscious episodes, for months.

Over the next two years, using *standard* treatments, she went from honors English in high school to being unable to comprehend a newspaper article. She would frequently sleep for 22 hours per day and attend school only 2 days per week.

We were concerned that she was dying, and ten years ago, we started her on antibiotics. While she was involved with multiple specialists, the most outspoken physician challenging her chronic Lyme diagnosis and long term antibiotic regimen was the seizure specialist at Dartmouth. We sought his opinion to rule out a secondary diagnosis of seizure disorder. This physician, whom I had known for years, said that she did not have Lyme disease, and as a professional courtesy, he would not report me for child abuse for giving toxic antibiotics to my daughter. These were not antibiotics that I prescribed; these were antibiotics prescribed by an infectious diseases specialist in Boston.

I am not accustomed to another physician suggesting that I am medically abusing my daughter. My wife was totally offended. I was much less so. I understood that his comments were based upon Infectious Disease Society guidelines.

.Yet, I have no doubt, that if he were willing to challenge my fitness as a parent for using antibiotics, I am sure he would be much more willing to challenge my professional competence.

On long term antibiotics, my daughter has improved.. She has graduated from high school, and college, and she recently finished her Masters Degree with a 4.0 average. I do not believe that her improvement on antibiotics was coincidental; nor that her diagnosis of lyme by CDC guidelines was coincidental to her neurologic problems.

Given my experience, how should I respond to the patient who presents in my practice with what I believe to be chronic Lyme disease? I have the backing of national ILADS criteria, and a wealth of supporting literature. Should I give my patient a choice of treatments, even if it puts my professional license at risk?

Kevin I. Young, M.D.

Attachment 4

New Hampshire Medical Society
For the betterment of public health since 1791.

THE FACTS ABOUT HB 1326 – LYME DISEASE

- The bill exempts physicians from Board of Medicine discipline for long term antibiotic therapy for Lyme disease.
- **No** physician should have a **blanket exemption** from Board of Medicine discipline!
- To date, no NH physician has been disciplined for prescribing long-term antibiotics for Lyme.
- Under current law, there is no restriction on the long-term prescription of antibiotics.
- Today, there is more awareness of the prevalence of Lyme in NH, so there is more early testing.
- Primary care physicians take this disease very seriously and NH is fortunate to have 26 Infectious Disease specialists.
- NH licensed physicians are required to meet the ***standard of care*** for all conditions they treat. It is inappropriate to specifically legislate what is currently NOT the standard of care. Medical standards do change; therefore they should not be put in statute.
- It is inappropriate to select **one particular disease/medical condition** or **one particular medication/treatment** and exempt physicians from having to meet the standard of care.
- HB1326 does not address **insurance coverage** for long term antibiotic treatment.
- There is **no evidence-based** study to show that long term antibiotic therapy is both beneficial and safe.

Attachment 5

ROBERT J. ANDELMAN, M.D.
President

AMY FEITELSON, M.D.
Vice President

PENNY TAYLOR
Administrator

ROBERT P. CERVENKA, M.D.
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MARK SULLIVAN, P.A.
BRIAN T. STERN, PUBLIC MEMBER
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April 26, 2010

TESTIMONY OF DR. ROBERT ANDELMAN
PRESIDENT, BOARD OF MEDICINE

Good afternoon, Senators.

I am here on behalf of the Board of Medicine. We have discussed HB 1326 at our meetings in April and March, and respectfully oppose it, for a number of reasons.

First, I would like to say that the vote to oppose HB 1326 was unanimous, and was made by the following individuals:

Amy Feitelson, a psychiatrist from Portsmouth, and Vice President of the Board.
Robert Cervenka, an obstetrician from Manchester.
Robert Vidaver, chief psychiatrist of the NH Hospital
Louis Rosenthall, a family practitioner from Concord
Nick Perencevich, a general surgeon from Concord
Mark Sullivan, a physician assistant in cardiac surgery from Portsmouth
Gail Barba, a public member from Concord
Brian Stern, a public member and attorney from Dover
Father Dan Morrissey, a public member from North Hampton.
And myself. I am an anesthesiologist from Portsmouth, have been in practice here in New Hampshire since 1973 with time out for anesthesia training in the mid-70's.

Second, I would like to say that at present, there has never been a Lyme related complaint, claim, or suit reviewed by the Board of Medicine. If one were to be filed with the Board, we would rely on appropriate consultants, whether they be in Infectious Disease, Neurology, Internal Medicine, or whatever else is necessary. We would rely heavily on their expert opinions, including consensus statements by the NIH or other appropriate national bodies. Thus, at this time, the Board takes no position on the clinical issues of treatment of Lyme disease, and physicians are free to prescribe appropriately. The Board would become involved only if there is a suit or complaint against a physician by a patient or family, or if there is a disciplinary action by a hospital.

Third, I would like to tell you that there is no precedent that the Board or its legal counsel knows of for this bill. We are unaware of any other disease, therapy, surgery, or mode of treatment which has statutory protection from oversight by the Board of Medicine.

Fourth, the Board sees this as an extremely dangerous precedent. Will other therapies or treatments be similarly exempt from Board oversight? Will the public now expect that through the legislative process it can compel physicians to practice in a certain way, either to perform or not perform a certain treatment or therapy?

I'll give you two concrete examples: Will the Legislature exempt a family practitioner or pediatrician if he or she chooses not to give a child vaccinations? Or will the Legislature protect such a doctor if he or she does vaccinate her patients?

Another example: Will the Legislature require a general surgeon to obtain a CT scan before he or she does an appendectomy, because CT scans are currently the gold standard of diagnosis? Or conversely, will the Legislature protect a general surgeon if he does not get a CT, for fear of excessive radiation?

The bottom line here is: who sets standards of medical practice? Is it the Legislature or is it physicians? Traditionally, the Legislature has left the practice of medicine to physicians, and the oversight of physicians to the Board of Medicine. Also traditionally, if a physician practices unsafely, or violates standards of practice, he or she is subject not only to the Board but to our tort system, a very powerful impetus to practice properly.

Fifth, the Board is aware that there are large numbers of our Citizens afflicted with a chronic illness for which there is not only no therapy, but no real diagnosis. We sympathize with those individuals who may be in constant pain, are in wheelchairs, or even bedridden. However, this is not a reason to violate our time tested system of leaving the practice of medicine to physicians, and the oversight of physicians to the Board of Medicine, with the availability of the tort system.

Medical standards and consensus evolve through research, debate, clinical trials, and a consensus of experts. There is no precedent in New Hampshire law for setting medical standards, and we should not start now.

For these reasons, the Board respectfully opposes HB 1326.

Thank you.

Attachment 6

Testimony before the Senate Executive Depts & Admin Committee

Good Afternoon. My name is David Hunter. I have been involved with Lyme disease as a Lyme patient advocate for the past ten years. Currently I am facilitator for the Greater Manchester Lyme Disease Support Group and Co-Chairman of the Bedford Lyme Disease Council. Amazingly, some thirty plus years after Lyme disease was first discovered in Old Lyme, CT, it is still a very misunderstood disease. Most people know all about early stage Lyme disease and the signs and symptoms to look for including a bulls-eye rash, joint pain, stiff neck and flu-like symptoms. Most doctors know that the standard treatment regimen for early stage Lyme is three to four weeks of antibiotics. On these points, there is general agreement. Disagreement comes when the illness moves beyond this initial stage and moves into the secondary and tertiary stages of the disease. If not properly diagnosed and treated in the initial acute stage, Lyme can become a highly debilitating illness. It is on this point that the medical community is divided as to how best to treat this later stage Lyme disease. The Infectious Disease Society of America (IDSA) has one standard of care which limits treatment to that initial four weeks of antibiotics. The International Lyme and Associated Diseases Society (ILADS) recognizes that the Borrelia burgdorferi bacteria that causes Lyme disease can persist well beyond the initial treatment phase and calls for more open-ended, long-term antibiotic treatment, if supported by clinical evaluation. Many people have greatly benefited from this standard of care.

HB 1326 does not legislate treatment. It only provides doctors the right to diagnose and treat clinically, as they have been taught in medical school, without fear of disciplinary action solely for treating Lyme patients with long-term antibiotics. We've witnessed medical boards in other states (CT,NY,NC) taking action against doctors for prescribing long-term antibiotic treatment for Lyme. We want to guard against this happening in New Hampshire. Connecticut enacted a similar law last summer. Here in New Hampshire and elsewhere, many doctors are reluctant to treat beyond the four week IDSA standard for fear that they might face repercussions for exceeding the four week limit. A law stating that doctors may prescribe long-term antibiotics for Lyme disease without fear of disciplinary action for doing so is likely to encourage more doctors to provide effective, longer-term care for Lyme disease, something we desperately need in this state. **Again, this bill does not legislate care**. It gives doctors the freedom to choose between the two valid, scientifically-based standards of care. Right now the NH Department of Health & Human Services only links to the IDSA Guidelines so residents aren't even being made aware of the second standard of care. The American Medical Association requires that physicians disclose and discuss the risks and benefits of alternative standards of care. Most doctors in New Hampshire are not making patients aware that there is a second option. This bill will help ensure that more Lyme patients have access to all available treatment options.

The IDSA opposes this bill and would like you to believe that they are the final authority on Lyme disease. They convey the belief that Lyme disease is an easily diagnosed, easily treated disease and that generally it cannot persist after four weeks of antibiotics. If properly diagnosed and properly treated in its early stage, it is a relatively easy disease to treat. However, if not properly diagnosed and treated soon after onset of the infection, it often becomes a far more debilitating, more entrenched infection that can impact a patient both physically and neurologically. This is where the IDSA & ILADS have very different fundamental viewpoints. **IDSA does not believe there is such a thing as chronic Lyme disease.** ILADS is adamant that there is. The IDSA would have you believe that all the scientific evidence is on their side. They like to contend that they practice evidence-based medicine implying that ILADS doesn't. This is nonsense. There are many studies that support ILADS' position that the Lyme bacteria, Borrelia burgdorferi, can persist despite weeks or even months of antibiotics. The scientific community has known for a very long time that syphilis can persist despite aggressive treatment, so why not Lyme disease? After all, Borrelia burgdorferi is a spirochetal bacterium, just as syphilis is and they share many of the same properties. It should not take much of a leap of faith to accept the possibility that Lyme disease can persist beyond four weeks of treatment. Yet the IDSA states that this is "microbiologically implausible" and attempts to portray the ILADS community as non-evidence-based and out on the fringe. There is a lot of science supporting the ILADS position while the IDSA position is the one that is ignoring much of the science.

This debate has much more to do with politics than it does science. The IDSA has a lot of clout, given their size and status as the pre-eminent authority on infectious diseases in the U.S.

They have used their reputation and clout to almost monopolize Lyme care in this country. The IDSA Lyme Disease Guidelines are the predominant guidelines followed by most of the medical establishment. Their guidelines have essentially been adopted by the American Academy of Neurology, the American College of Physicians, and the American Academy of Pediatrics, among others. Is it because their guidelines are superior? **Not at all!** It is because of their authority, status and the aggressive campaign they have waged to discredit ILADS and the ILADS guidelines. The truth is that the IDSA stranglehold over Lyme care in this country is causing an incredibly large number of people to be left without access to effective care for their progressive, debilitating illness. Guidelines are supposed to be exactly that, **guidelines.** But because of the IDSA's aggressive campaign, its guidelines have become a virtual mandate.

New Hampshire ranks at the top in the per capita incidence of Lyme disease. The turnout for this hearing today speaks to this. Throughout this afternoon you will hear testimony from people who have lived the horrors of this terrible disease. You will see from their testimonies that Lyme can cause serious physical and mental disability as well as economic hardship. You will see that what many of the patients will describe here is nothing remotely close to the IDSA's description of lingering symptoms as the vague aches & pains of everyday life. Without more doctors who are willing to treat Lyme patients beyond the IDSA four week limit, we will continue to see the numbers of chronically ill NH residents rise dramatically. We desperately need this bill to allow doctors to treat patients according to their best clinical judgment, without fear of disciplinary action. Without it, Lyme disease will continue to take an ever-increasing toll on the state in terms of rising healthcare costs, soaring special education budgets and lost productivity. Now, I would like to ask that every NH resident in this room who has Lyme disease, please stand if they are able to do so. Please support HB 1326. These people are counting on you. Thank you.

David Hunter
Bedford, NH

Attachment 7

Dartmouth-Hitchcock

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Jeffrey Parsonnet, M.D.
Professor of Medicine
Section of Infectious Diseases and International Health

Date: April 26, 2010

To: Senate Executive Departments and Administration Committee

Re: HB 1326. An act relative to the use of long-term antibiotics for the treatment of Lyme disease.

Chairwoman Cilley, Vice Chair Clark, and Senators Downing, DeVries and Carson:

My name is Jeffrey Parsonnet. I am a member of the Section of Infectious Diseases and International Health at Dartmouth-Hitchcock Medical Center. I also carry the academic title of Professor of Medicine at Dartmouth Medical School. I am a fellow of the Infectious Diseases Society of America (IDSA) and a member and past president of the Northern New England Infectious Disease Society (NNEIDS), which represents ID physicians from the states of New Hampshire, Vermont and Maine. I recently served on IDSA's Lyme Disease Guideline Review Committee, which was established in response to an antitrust investigation begun in 2006 by the Attorney General of the State of Connecticut. More importantly, I have an active clinical practice at Dartmouth-Hitchcock, a large component of which is seeing patients with Lyme disease. I consider myself to be knowledgeable about Lyme disease, but I have not been politically active in this area and I have never testified before a legislative body about this or any other issue.

It is my honor and pleasure to have been asked to comment today on HB 1326, the purpose of which is to protect NH physicians from disciplinary action for treating patients who have been "clinically diagnosed with Lyme disease" with long-term antibiotics. I am officially here as a representative of Dartmouth-Hitchcock Medical Center, but I believe my views also reflect those of other members of my Section, and of IDSA and NNEIDS. We are opposed to HB 1326 because its effect would be to prevent the Board of Medicine from conducting its legally mandated role of medical practice oversight in the State. The Board of Medicine was established by the legislature because a lay body lacks the knowledge and expertise to oversee medical practice. HB 1326 would establish a dangerous precedent for other diseases or procedures for which there are disagreements about guidelines for the practice of Medicine. Why should Lyme disease be singled out in this regard? Would the legislature similarly strip the Board of its task to oversee treatment of cancer and heart disease, allowing administration of unproven cancer treatments or performance of obsolete interventions for heart disease?

Being an ID physician, I would like to make several specific comments about HB 1326 and Lyme disease. In thinking about Lyme it is important to remember a couple of things. First, there are signs and symptoms of acute Lyme disease that are relatively easy to recognize – most notably a characteristic rash – and there are signs and symptoms of chronic infection, many of which are "nonspecific," which means they can be seen in a variety of illnesses other than Lyme. In the practice of medicine we are always looking for "objective" signs of an illness, as they make us more confident of our diagnoses, and more willing to subject patients to the costs and risks of therapy. In chronic or late-stage Lyme, examples of objective signs include abnormal heart rhythms (heart block), facial nerve paralysis, and swollen joints; examples of subjective symptoms include fatigue, problems with concentration and memory, mood disorders, and neuropathic pain, all of which can be severe and debilitating. Second, there is a difference between having an active infection, which means that the causative organism – whether it is *B. burgdorferi* or tuberculosis or MRSA – is alive, and having symptoms that reflect a prior infection that has been eradicated. (Bacterial infections such as Lyme can be eradicated by antibiotics, whereas some viral infections, such as HIV, remain active despite treatment.) There is no question that patients who have had Lyme disease, even properly treated by anyone's standards, *can* have persistent symptoms. At issue, however, is whether this reflects ongoing infection, in which case continued treatment with antibiotics would be a rational and effective approach, or whether they are persistent sequelae of prior infection, in which case they would not. Nobody would deny that symptoms that persist after a person has been treated with antibiotics for Lyme disease require treatment; the question is whether long-term antibiotics are an appropriate treatment, and controlled data do not support this approach.

This bill defines Lyme disease as a "clinical diagnosis" in patients with signs and symptoms compatible with acute infection, or with persistent or chronic infection with *Borrelia burgdorferi*, or with complications related to such an infection. Again, acute infection with Lyme is relatively easy to recognize and a clinical diagnosis does not require laboratory confirmation. In New Hampshire, most cases of Lyme disease are acquired during the months of April through August. There is no disagreement about the need to treat patients with active infection with antibiotics (or the infection could become chronic), and fortunately, antibiotics are very effective. For example, a recent study published in Clinical Infectious Diseases looked at 607 patients with acute Lyme. Patients were treated with antibiotics for various lengths of time, and there was only a 1% failure rate; the success rate of treatment with antibiotics for 10 days or less was 99%.

Diagnosis of chronic Lyme disease, which can occur when patients are not treated early in the course of infection, can be more difficult. The vast majority of patients develop antibody to *B. burgdorferi*, and antibody can be found using conventional tests performed by many laboratories around the country. Testing is imperfect, as we all know, but the truth is that most patients with persistent infection have circulating antibody to the organism. HB 1326 refers to "the surveillance criteria set forth by the Centers for Disease Control and Prevention." For the record, these criteria are (to paraphrase):

- Physician-diagnosed erythema migrans, or
- At least one *objective* late manifestation of Lyme, with laboratory confirmation of infection with *B. burgdorferi.*

The bill, as written, does *not* conform to these criteria, in that it allows for a clinical diagnosis based on nothing more than a physician's medical history and physical examination alone.

Fortunately, again, antibiotics are highly effective at eradicating infection with *B. burgdorferi* even in its late stages, although treatment for at least one month is often required, and the failure rate is slightly higher than when treating acute infection. At issue today is whether patients with long-term symptoms *despite adequate treatment* for Lyme stand to benefit from prolonged course of antibiotics. As you all know, this question was put to the test in a rigorous, double-blind, randomized study, the conclusion of which is that patients who have received adequate therapy *do not* benefit from months or years of additional antibiotic therapy.

Again, the point I am here to emphasize today is not that Lyme disease should be treated with any specific regimen for any specified period of time, but whether the legislature should undermine the Board of Medicine's responsibility to oversee the use of antibiotics for treating Lyme. I have absolutely no conflict of interest , nor any ulterior motive in addressing you today on this issue. My primary concern is to ensure the best quality in patient care and to protect the public's health and safety. To this end, I believe it is critically important to point out that the Board of Medicine consists of physicians whose responsibility is to protect the health of the public and who have expertise and training that members of the state legislature do not have. It is inappropriate and potentially dangerous for elected officials to usurp the Board's role.

Lyme disease provides a specific example of why medical decisions must be based on scientific evidence, rather than undue political influence. Inappropriate use of antibiotics, especially intravenous antibiotics, can put patients at risk of serious bloodstream infections, serious drug reactions and *C. difficile*-associated diarrhea, as well as the enhancing emergence of antibiotic-resistant bacteria or "superbugs." As noted in the report put out by the Lyme Guideline Review Panel, which you have at your disposal: "In the case of Lyme disease, there has yet to be a single high quality clinical study that demonstrates comparable benefit to prolonging antibiotic therapy beyond one month." The report also noted that "the inherent risks of long-term antibiotic therapy were not justified by clinical benefit." The Board of Medicine should be able to make decisions based on hard science, without politically motivated influences.

House Bill 1326 seeks to carve out a special exception that protects physicians who prescribe certain treatments from disciplinary action by the New Hampshire Board of Medicine. In essence, the New Hampshire General Court is being asked to usurp the authority of the Board by making a medical decision on the validity of certain Lyme disease treatments. But even more troubling is the precedent that this bill would set; an affirmative vote on this bill would send a message that other patient groups and doctors, who believe in the efficacy of unproven (and perhaps dangerous) medical treatments, can count on the Legislature to allow them to practice unsafe medicine.

I commend this Committee's efforts to hold public hearings on Lyme disease. It is my hope that this hearing will play an important role in educating New Hampshire residents about appropriate treatments for Lyme disease. If the Committee requires further guidance, it has been suggested that a special legislative commission be established, a group made up of physicians (of my specialty and in general practice), that would be charged with studying all aspects of how to prevent, diagnose, and appropriately treat Lyme disease in New Hampshire. Such a commission could provide a fair and balanced report back to the Committee.

Thank you again for allowing me to address the Committee today. I look forward to the opportunity of working with you on this issue, should you request additional input from the ID community.

Attachment 8

My name is Jacqueline Arlen and I am here today with my hero, my daughter Victoria. She has an advanced chronic tick borne infection and according to the ~~American Medical Association~~ IDSA what ailes my daughter does not even exist.

I think it is important that you understand what has gone on these last five years but before I briefly tell our story I would like to emphasize what I feel to be a very valid point that needs to be made today. We can argue back and forth all day on the use of long term antibiotics and protecting our NH doctors but at the end of the day I believe it is about patient advocacy. If our doctors were made to feel more comfortable about treating patients with Lyme maybe we would get more doctors involved and learning about this infection. What we as patients need are more doctors in this state who are just willing to listen and at least attempt to try and help us. We as a family were alone with only one Lyme doctor advocating for us and he is now no longer practicing because of the pressures that were subtly put on him and his practice. Victoria has damage to her spine because of this infection and this could have been avoided had her primary care practitioner just believed her in the first place and tried to help us. She has completely lost these years of her childhood, years that she will never get back.

Our journey began in March 2005 when Victoria was bitten by a tick. I had brought her to her pediatrician because of a red swollen ear, was given cortisone cream and we were sent on our way. What I did not realize was that the doctor had noticed a small puncture wound in her ear and had made a note in her chart that it was a possible bug bite but had neglected to tell us. What followed was a text book case of Lyme disease and that following year she was plagued with the flu, high fevers, fainting spells, exercise induced asthma amongst many other strange ailments. As I am sure you are all aware Lyme disease is quite curable if caught early and antibiotics are given. She was back in the pediatrician's office every few months...this from a child who at most went once a year for well check ups. Because we never knew there had even been a bite in her ear we just assumed her immune system was out of whack. Despite all of this Victoria continued to excel in everything that she did—she started middle school, made the field hockey team as a fifth grader, continued to do well in swimming and was a high honor student. She used to say..."I just don't feel right."

What happens with this infection if left untreated is that is goes into advanced stages and that is exactly what happened to Victoria. On April 29, 2006 she woke up with terrible pain on her right side. After a few days it was assumed to be appendicitis and her appendix was removed. She never recovered after the surgery. Within weeks she lost fifteen pounds and her legs started to give out on her. By the middle of June she was paralyzed and we were ordering a wheel chair. She started to have trouble swallowing and we were losing her cognitively. All the while she was in insane pain twenty four hours a day. She used to cry herself to sleep and even cry in her sleep. It would take doctors eight months before a pain team took the time to diagnose it as neuropathic and start to treat it. Her doctor who had had her as a patient since birth and had missed the very obvious said she was doing all this for attention because she is a triplet. It was all in her head and Victoria was incredibly insulted by this. We were watching her fail and we were alone. It was taking a huge toll on our family. By the middle of July she lost her memory and did not know who we were, who she was or where she was. Can you even begin to imagine what it is like as a mother to have your child look at you in terror and not know who you are? After four stays in major medical institutions the doctors were of no help and after minimal testing unbeknownst to us they were all going down the psychiatric route. I will not get into details of that horrible time that summer in a prominent Boston hospital but what they did to her was horrific. To this day our family is brought to tears at the thought of how we almost lost her at the hands of the "best in the world."

I would like anyone who has children to imagine for a moment what it is like to hold your limp unresponsive dying child in your arms and have no where to turn and no doctor to help you.

After major perseverance and research I figured out that she had all the symptoms of Lyme disease. She was diagnosed by a prominent local Lyme specialist (who I had stated earlier is unfortunately no longer practicing) and she started treatment.

What is amazing to me is that doctors acknowledge that early Lyme disease exists and that a course of antibiotics should work to cure it yet they will not acknowledge the cases like Victoria that are missed and turn chronic. I challenge any one of you to look into my daughters eyes and tell her what she has does not exist.

To this day Victoria is fighting the fight and does it with amazing grace and has a spirit that melts all of our hearts. I will continue to advocate on her behalf. Our dream is that other children in this state will not have to suffer as she has.

Victoria has a you tube video tribute by her cousin...you must watch it. "Lyme disease, Victoria's Victory 2009"

Attachment 9

Statement for Lyme Hearing:

My name is Marie Veselsky. I am a Certified Diabetes Educator and a Registered Dietitian and have worked in health care over 20 years. I currently work as the Coordinator for the Diabetes Center at Speare Memorial Hospital in Plymouth NH.

My testimony today is for the doctors in New Hampshire, who should be able to practice, without fear of reprisal for prescribing longer term antibiotics for Lyme.

I personally do not know how long someone should be on antibiotics for Lyme, the magic time frame. What works for one person may take longer for another. The doctor along with his or her patient should be able to make that decision. I do believe though that the longer term antibiotics saved my life.

I never fathomed in my wildest dreams that it would take ME 11 months to finally be diagnosed with Lyme. 11 months to finally get one course of antibiotics! All because my first Lyme test the ELISA was negative and my second Lyme test the Western Blot was CDC negative. I believe the current testing and treatment guidelines allow people to fall through the cracks.

Starting in ~June of 2005 - severe night sweats, fast heart rates of over 130 just standing, heart palps at night so bad that if I laid on my side I could hear my heart pound loudly in my ear, and thus I often slept sitting up in a chair, muscle aches, unexplained bruising, shortness of breath just walking up a few steps, exercise intolerance, dizziness, insomnia and extreme fatigue.

A former long distance runner, who just months before was setting records in her age group at races. Yet, because there were no abnormal labs, including the Lyme test, and all heart tests came back normal except for sinus tachycardia and insignificant T wave changes, I did not get diagnosed with anything.

April 2006, almost 11 months after my symptoms began, I found out that Lyme tests are not always accurate and I gave Lyme another look. A family physician, did extensive testing, and I was finally clinically diagnosed with Lyme.

At first, I was just glad I knew what I had; then months of "herxing" so bad I could barely get out of bed; the antibiotics were obviously hitting their mark. I obviously had some type of serious bacteria infection that the lab tests did not pick up. I was on consistent antibiotics ~8 months. From ~May 2006 – January 2007.

Now, it is April 2010, s/p antibiotics 3 years and ~4months. I am well again! No longer will I take for granted the things I lost like the ability to sleep, walking up a flight of stairs without being out of breath, muscles pain free. I am able to run again every day if I want and I feel lucky. I ran the Mount Washington Road Race June 2008 about 1 year after stopping antibiotics. This was from a woman who could not climb 3 steps without being out of breath before getting the antibiotics I needed. I ran the 5 mile Red Shoe Barn Race in Dover this last Sunday. I have also made the lottery for the Mount Washington Road Race on June 19, 2010. I will celebrate being given another chance at life. Not everyone is so lucky.

It would be easy to just move on with my life now that I am feeling better. Forget about what a long journey it was to get the care I needed. But I remind myself that I was out there once hoping someone would help me. I feel it is my obligation to help those that may fall through the cracks like I did, and I want to support my doctor. My doctor stuck his neck out for me...I am here today literally because of him. I am a Race Director for a Half Marathon in Plymouth coming up this July. It benefits the Pemi Youth Center and the Homeless Shelter. I can give back. I am able to do this because my doctor did the right thing even though he was going against the standard guidelines.

What I have always found interesting is that for a disease that supposedly does not exist, Chronic Lyme, there sure seems to be a lot of people who know someone affected by it. Your neighbors, co-workers, a friend of a friend. I am sure you want them to get the help they need.

Please protect a doctor's right to make clinical judgments about the diagnosis of Lyme and the length of time patients are on antibiotics. I know without a doubt 3 weeks of antibiotics would not have been enough for me.

Marie Veselsky MAOE, RD, LD, CDE

Attachment 10

My name is Jess. I am 18 years old and a senior in high school. I was diagnosed with Lyme Disease last spring, but my symptoms can be traced back almost 5 years. I will not get into the details of my illness here, but I will say that I realize how extremely lucky I was to be clinically diagnosed by a Lyme literate doctor based on my symptoms, as I never had a rash and all my tests came back negative or indeterminate. I've since learned how unreliable the testing is. At first we were so happy just to have a diagnosis, but as we learned how difficult it is to receive the treatment I would need, our reaction was more guarded. We were actually on the verge of doing what so many others have done and going out of state for treatment because our doctor was so busy with Lyme patients that it ~~is~~ was incredibly difficult to get in, but we stayed because of the time and money it would take to go out of state. You see there are only a handful of doctors who will treat chronic Lyme in this state. ~~They~~ The others either don't know there are two standards of care, or are afraid to use long-term antibiotics because of the CDC guidelines. The CDC does not even recognize chronic Lyme as a disease, which is very confusing to us, because isn't a disease chronic by definition if you have had it for a long time? They are against the use of long-term antibiotics because of possible side effects they may cause. What about the possible side effects of chemo and radiation? Believe me, when you are looking at a life in bed or death vs. some possible side effects from your medication, there are many for whom the choice is easy. ~~but~~ The ability for Lyme patients to make ~~it~~ that decision, however, is hampered by current guidelines which affect doctor's decisions to treat.

Fortunately for me, my doctor started me on antibiotic treatment based on my symptoms. After an initial Herxheimer reaction, I **started to** feel better. Again, fortunately for me, my doctor understands that it may take a lot longer than 30 days of antibiotics to treat a chronic Lyme patient. By the time I was diagnosed I was basically bedridden from the pain I was in. If my doctor had followed the IDSA guidelines, I know that I would certainly not be here before you today because I was not any better after their recommended course of antibiotics, ~~and~~ After 30 days, I was wondering at that point if I would ever have a normal life again.

It has now been exactly one year since I started treatment, and the improvements are miraculous - every day I discover new indications that I am recovering. I now attend school almost full time, where as I used to go only 1 or 2 days a week, if that--this year alone I have missed 64 days of school. I also got accepted into UNH with a presidential scholarship, which is an amazing improvement from the girl last fall who sat crying at her computer because she could not form a sentence to write an essay. I got straight A's on my report card last quarter, too, although that would not have been possible without a 504 plan and the understanding nature of my teachers. One of the hardest parts, though, has been trying to explain to my friends what I'm going through, because when I go to school everyone says, "Well you *look* fine, you don't *look* sick…" And its true that with Lyme disease you often don't look as sick as you feel. In my case, it attacked my central nervous system and my brain, and I didn't have many noticeable physical symptoms. A stranger off the street would have no idea of how sick I am. And I believe that is one of the most challenging aspects of Lyme, and why so many people hear that "it's all in their head" and that "there is nothing wrong with them." It took a very astute, Lyme-literate doctor to recognize what was going on with me, and to treat me accurately based purely on my symptoms.

I'm here today on behalf of all the other patients who could not make it because they are in the same situation I was a year ago. I am here in an effort to **prevent** doctors in this state from ever having to face the incriminations that so many other doctors in the US have already been subjected to. I'm also here because if this bill is passed into law, other doctors will not be afraid to take on patients with Lyme, and will be more inclined to become educated on the two standards of care and on the disease itself. The lack of general knowledge amongst the public is one of the biggest obstacles we face. Think of the AIDS epidemic back in the 70s…there was so much ignorance and misunderstanding about that disease then, and reading the guidelines 40 years later one would be astounded at the misinformation presented. I am here because I do not want to wait 40 years to see this disease understood, when there is already so much valuable research out there. The only way to prevent that from happening is to take it upon ourselves to be proactive in making ~~our efforts to make~~ the public aware of this disease, and to simultaneously protect them from it.

I would just like to end by saying that if anything ever happens to my doctor to prevent me from receiving the rest of my treatment, I'm not sure what I'll do. The girl here before you ~~is one~~ today is one who finally feels as though she has gotten her life back. It is absolutely terrifying to think that a relapse from lack of treatment could so easily take that all away again.

testimony 4/26/10

I had Lyme for between 3-5 yrs undiagnosed.

Diagnosis was a relief (an answer to all the mystery) until I realized what a long road ahead it was to recovery. In the process, introduced to the secret world of Lyme Disease.

Here today in hopes that the Senate will send this bill through so that more doctors will a) become aware of two standards of treatment for disease and b) be willing to treat with long-term antibiotics when necessary

If I'd had only 30 days of treatment I would most certainly still be bed-ridden and contemplating how much better I'd be off dead. Most chronic Lyme patients would much prefer the "risks" of long-term antibiotics over the non-life that they have.

Don't understand the IDSA's reluctance to change guidelines, recognize that chronic Lyme exists. If you've had this disease more than a month without it being diagnosed, it is by definition chronic. If you've had it build up in your system for years, how is 30 days of antibiotics going to kill a bacteria that is so slow to reproduce that they do it every 28 days instead of every few hours like most bacteria?

Hope we can be proactive here in our own state. It's the only way to start to send a message to the IDSA that although they don't accept any of the scientific studies that show long-term antibiotics are helpful to chronic Lyme patients, there is living proof in all the people in this room who have benefited from taking the time to find one of the few doctors who would treat them until they were well, instead of only for 30 days.

Attachment 11

My name is Pete Ballou and I have Lyme disease. My non-Lyme literate doctors misdiagnosed me for three years. During that time my vision changed radically. I progressively became confused and developed memory loss and severe tremors. My balance and coordination became so bad that I was bedridden. I have been in the hospital twice in the last year. I have not worked in over a year and I had to stop driving. I stopped doing every activity that I have enjoyed in my life. The doctors would not investigate the possibility of Lyme disease and I had to get a western blot test outside of my medical system. I had to change my primary care physician after he refused to acknowledge the western blot test results.

There are only a few Lyme literate doctors in New Hampshire. Mine did a thorough workup on me and he has helped me to improve my overall health as well as treat the Lyme disease-something that my previous doctors failed to do. My other doctors never told me about the ILADs guidelines. They only referenced the IDSA guidelines. I was never given a choice and they even refused to give me a western blot test even though I begged them for one and offered to pay cash for it. They just told me that they didn't know what was wrong with me, I would have to learn to live with it, and there was nothing else that they could do for me.

My Lyme literate doctor is the only one out of fifteen doctors that I have seen who has said that he can help me to get better. I have been on long-term antibiotics since January of this year and I am slowly getting better. My eyesight has shown some improvement and while I still have bad days, I am starting to feel like a human being again. I can't put in a full day's work yet but I am looking forward to that day. I have finally found someone who is willing and able to help me and I am very concerned that he may someday have his license taken away for treating Lyme disease patients with long term antibiotics. My doctor is also concerned that if this legislation doesn't pass, he will be targeted. Please keep in mind that New Hampshire has the highest Lyme disease infection rate per capita in the country and the charts are going straight up.

House Bill 1326 does not shelter doctors from responsibility. It will offer a choice. By passing House Bill 1326 you are not only ensuring the safety and proper treatment of Lyme disease sufferers in New Hampshire, it will also create an environment where other doctors will feel safe to become Lyme literate too. Please help me and all of the people in New Hampshire with Lyme disease by voting in favor of this bill. Thank you for your time.

Pete Brooks Ballou

#38 Pepperell rd. Brookline N.H,

Attachment 12

26 April 2010 New Hampshire Senate Hearing on HB 1326
Lyme Disease Bill

Anthony Dreux Fallon
501 Barn Door Gap
Strafford, New Hampshire 03884
603 269 3206
tony@tonyfallon.com

My name is Tony Fallon from Strafford and I have been dealing with Lyme Disease for 30 years. 4 out of 5 of my family members have Lyme and I find this topic like being in the Wild West. Thank you for your service. I also thank Jesus, God, & The Holy Spirit for the many blessings that we are showered with.

We plead for you to Construct the 1326 Shelter for Doctors to Enable them the Freedom to Fully Practice.

The Dark Hat Opposition rests in the four sound bites of Science, Danger, limiting malpractice, & Legislating Medicine. I attest and assure you that The White Hat Doctors of ILADS who do recognize the existence of long term Lyme Disease do so based on Internationally Recognized Science. I further attest and assure you that the Black Hat efforts to Forbid the Recognition of long term Lyme Disease is the True & Real Danger. It is also a Crime and a Sin as it allows this disease to go from Total Cure to a Life Long Life Changing, Life

Threatening, Plague. I further attest and assure you that there is nothing in this legislation that limits recourse for genuine malpractice. 1326 limits Disingenuous Malpractice only. The final sound bite of "Legislating Medicine" is an attempt to scare you into thinking that you are becoming responsible for health care decisions. Take heart, this is an absurd claim. We instead are pleading with you to legislate a shelter for the good Doctors with the White Hats of ILADS to protect them from Black Hat attempts to keep them from considering more than one standard of care.

As an Architect I create shelter for people to Operate. Bill 1326 will provide Needed Shelter for Doctors to Optimally Treat this Dastardly Disease by Enabling them to Consider All Possible Protocols. If the situation wasn't so tragic the absurdity of these Black Hat IDSA efforts would be great comedy. Mandating one standard of care is akin to requiring that all buildings be built with one material.

And for the question as to why is this something that needs to go through the legislature and not the State Medical Board, the answer is simple. As you have heard today and was stated in the February 21st State House Dome Column in the Union Leader, Our State Medical Director is wearing a Black Hat and is endeavoring to convince you that this dastardly, debilitating, sometimes fatal disease doesn't exist. Bill 1326 will build a shelter from the Black Hat Foxes who have been ravaging the hen house, the results of which are arrayed in front of you.

I further attest and assure you that I know doctors who have not shown up to testify due to fear for their careers. I have driven to hundreds of appointments in Connecticut and New York and at one time we had out of pocket costs of 3,000 dollars per month.

Please Construct the 1326 Shelter to Enable Doctors the Freedom to Fully Practice. The Connecticut Senate voted the same bill up unanimously. It's a fitting suit to follow. Thank you.

Lyme Disease is a terribly harsh disease.

(Double speak
Leave it to physicians)

~~[illegible]~~

Having to treat such a harsh disease from a terribly harsh environment is something you i 1326 can fix here now for your constituents.

(• employers pushing)
• insurance co pushing

(special [illegible] for missing [illegible])

Practice left to the physicians

How many Lyme Specialty Practices are there in NH?

From: Anthony Dreux Fallon <tonyfallon@me.com>
Subject: **Fwd: Lyme Treatment Freedom Bill to New Hampshire Senate .... 700 word piece .....**
Date: February 23, 2010 6:32:32 AM EST
To: Senator Kathleen Sgambati <kathleen.sgambati@leg.state.nh.us>

Dear Senator Sgambati,

Thank you again for your service.

I hope to give you a call sometime and for now copy you with some more that I have written on this topic. The first I sent out today to the papers and the second is how I responded online to the Sunday State House Dome piece in the Union Leader. Trying pretty hard to pave the way for other families.

Wishing all the best,

Tony

Begin forwarded message:

From: Anthony Dreux Fallon <tony@tonyfallon.com>
Date: February 23, 2010 6:23:12 AM EST
Subject: Lyme Treatment Freedom Bill to New Hampshire Senate .... 700 word piece .....

Heartening. It was so heartening last Wednesday 17 February 2010 at the New Hampshire Hall of Representatives to see the board light up with a resounding & historic 300 to 56 vote for HB 1326, The Lyme Disease Bill. Heartening after so many years of unnecessary suffering, with my three children and my wife having Lyme Disease, to see New Hampshire a step closer in allowing doctors to care with clarity for those challenged by this very damaging, ever changing disease. It was heartening to see our representative system of government work even when the few, well connected, and powerful put up well heeled opposition. It was heartening to see our New Hampshire Legislature hear their constituents and unite to create shelter for doctors to freely see and then diagnose Lyme Disease in a long term form.

Thank you all. Thank you God. Thank you citizens for participating. Thank you Representatives for listening and representing. Thank you to those who sponsored and drafted the bill. Thank you to the Representatives who composed and delivered the eloquent floor speeches.

My wife spent many years with tests for Lupus, Multiple Sclerosis, and more before we finally found that my wife had Lyme Disease. And then, we were shocked to discover a hostile environment for doctors who diagnose and treat for longer term Lyme Disease. Stamford, Connecticut is 5 hours from Strafford, New Hampshire by car. I drove many trips to a doctor there we found brave enough to battle both the disease and the hostile attacks on his business. He has since moved to Manhattan and we followed. Many New Hampshire families have done the same distances. One of that doctor's telling quotes after the move was that this was "Custer's Last Stand." This move was prior to Connecticut enacting their Lyme Disease Legislation. He had endured years of bizarre harassment as had most Doctors who diagnose and treat for longer term incidences of Lyme Disease.

With the harsh environment, and the result of doctors fearing for their business life, tragic flourishing of Lyme Disease occurs. If our doctors were free to practice medicine as they saw fit for the optimal benefit for their patients, then we could catch this disease in it's infancy and eliminate it from the patient. Our doctors could then help us avoid blindness, loss of motor function, loss of cognitive function, numbness, pain, death, and more. Doctors need to be allowed to consider and, if they find best, utilize the International Lyme and Associated Disease Associations, ILADS, Guidelines among others.

The result of delayed diagnosis and treatment then is significant, horrific, and unnecessary. It would seem simpler to cut off the harassment at the source. The State of Connecticut found that it is better to go at it from both ends. Belts and Suspenders as we say in Architecture when designing shelter. In addition to the State of Connecticut's Attorney General filing suit against the Infectious Disease Society, IDSA, to endeavor to disable the source of consternation, the Legislature voted to provide shelter too. In fact, as New Hampshire Representative Cebrowski beautifully presented on the floor in Concord, the legislature in Connecticut voted up this bill unanimously in both the Connecticut Senate and the House of Representatives. No votes against this virtual twin bill which has passed our House 300 to 46 and is on the way to the our Senate.

The ILADS website is robust with scientific rebuttals to the lame claims that diagnosing and treating Lyme in longer term forms still needs to achieve a scientific basis. The 02.21.2010 Union Leader State House Dome Column by Tom Fahey illustrated the hostile effort to forbid doctors to consider "multiple standards of care" such as ILADS guidelines, by none other than our state health director. I further rebutted this assault in the online version of that column. We see again that IDSA has undue influence in medical arenas of authority and hence the need for HB 1326.

Thank you again and please continue to participate. Call your State of New Hampshire Senators and ask them to construct a shelter for doctors so as to allow them to freely treat their patients for Lyme Disease at all stages. Please.

> On the Lyme Disease Bill. First, It was a resounding and historic approval, 300 to 56. Second, it is basically the same bill passed in the State of Connecticut unanimously in both the Connecticut House and Connecticut Senate as Representative Cebrowski testified. No votes against in either body. Third, despite the claim in the Dome piece to the contrary, there is a vast body of science showing that Lyme Disease can occur in a long term form and that long term antibiotics can assist greatly. Refer to the website of the International Lyme And Associated Diseases Society at http://ilads.org and particularly to the position paper, "Evaluation of Antibiotic Treatment in Patients with Persistent Symptoms of Lyme Disease: an ILADS Position Paper" by Stricker and others. This paper specifically shows the scientific based benefit of treatment. There is much more information at ILADS website that is helpful. I also can attest with what I have experienced as husband to my wife and father of three children whom have all had long term Lyme Disease. Fourth, HB 1326 does nothing to limit malpractice. What it does do is provide shelter for doctors wanting to recognize the existence of long term Lyme disease, diagnose long term Lyme disease when they find it, and offer to their patients a scientifically proven, internationally recognized standard of care. It is exactly the effort to forbid other "standards of care" by our State Health Director in the Dome piece that illustrates the need for shelter for the doctors. HB 1326 will provide this needed shelter and result in better care for the patients and citizens of New Hampshire. New Hampshire has the highest per capita incidence of Lyme Disease and many people, including my family, have had to travel to Connecticut and New York to find appropriate care due to the harsh environment for doctors that HB 1326 will correct. With my family's experience, I know that Lyme Disease itself is bad enough. To then have the freedom of our doctors limited is too too much. HB 1326 does not, "legislate medicine." HB 1326 allows for the freedom of doctors to practice as they see fit to

best serve their patients. Freedom, please.

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As your word unfolds, it gives light,
and the simple understand.
Psalm 119:130

From: Anthony Dreux Fallon <tony@tonyfallon.com>
Subject: **Lyme Disease Bill**
Date: February 17, 2010 8:27:51 PM EST
To: kathleen.sgambati@leg.state.nh.us

Dear Senator Sgambati,

Thanks for your service.

I am a constituent of yours and appreciate the time and resources you contribute to the State of New Hampshire.

You may have heard the the Lyme Bill HB 1326 passed the House 300 to 56 this morning. I have been encouraging the passage of this bill and am buoyed by the outcome.

I pray you consider this legislation favorably and either my wife, Erin, or myself would be more than happy to discuss the topic. As you will see below in what I paste in, with 4 out of 5 family members with Lyme and travel to Connecticut and Manhattan for treatment, we speak from experience.

Hope the Winter is fun for you and yours!

Wishing all the best,

Tony

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As your word unfolds, it gives light,
and the simple understand.
Psalm 119:130

> **From:** Anthony Dreux Fallon <tony@tonyfallon.com>
> **Date:** February 15, 2010 10:54:49 AM EST
> **To:** undisclosed-recipients: ;
> **Subject: Please contact New Hampshire Representatives prior to Wednesday vote on Lyme Bill HB 1326**
>
> Hi,
>
> Due to the importance and the immediacy of this topic, I am sending this out to those whom I have in my data base with a New Hampshire address. I hope for both your understanding and support.

I ask you to please participate as a New Hampshire Citizen in gaining the passage this Wednesday the 17th of HB 1326 in the New Hampshire State House of Representatives.

Some of you may know that my wife and three children have had Lyme Disease.

It is caused by a bacteria that, if caught early and treated early and vigorously enough, can be knocked out.

However if it is allowed to flourish, it can cause a broad spectrum of symptoms that are ever changing as it mimics our makeup and so hides from our immune system. It can also then cross into the otherwise super safe separate blood system dedicated to our brain and spinal cord. Once into the control room, opportunities for havoc are boundless. These particular bacteria can go through most barriers due to a corkscrew structure and they can hide dormant for years in a cyst form and then return to activity. This often thwarts diagnosis.

Unfortunately as devastating as this disease is, the tragedy is unnecessarily multiplied by a bizarre assault on doctors who diagnose and prescribe effective & successful treatments. Frequently and consistently they are brought before their state's licensing boards in efforts to have their licenses pulled, threatened with being fired, hired only if they promise to not treat for Lyme Disease, or refused hospital privileges among other actions.

These career threats on their business life of course makes it difficult, and in most cases impossible, for them to treat for Lyme. Many seriously sick people from New Hampshire are having to travel 4 to 6 hours one way to find doctors who have appropriate legislative shelter that permits them to focus on care.

With illogical things, trying to find the source of this confused assault can boggle the mind. Often if we can just get to the source and straighten it out then things will improve downstream. In this case though, we need to focus and immediatedly build shelter for the doctors. It will allow for sorely needed vital improvement.

And so here is how I beg you to participate in this experiment in self governance. On this coming Wednesday the 17th, the New Hampshire House of Representatives has a series of bills that it is voting on and near the top of the list is HB 1326. HB 1326 will provide shelter to those wishing to treat for Lyme Disease. It is short sweet clear and effective. Here is the meat of it:

"No licensed physician may be subject to disciplinary action solely for prescribing, administering, or dispensing long-term antibiotic therapy for a patient clinically diagnosed with Lyme disease ..."

Please go to

http://www.gencourt.state.nh.us/ns/whosmyleg/

and find your legislators and ask them to vote **OTP or Out to Pass** HB 1326 on this Wednesday the 17th.

Please ask them **not** to kill it.

Please ask them **not** to send it to interim study.

Please.

It is so much more effective for the legislators to hear from their own constituents.

Also, if you have the time and stamina to make a few other calls, it would be helpful if you could call those on the Health, Human Services, and Elderly Affairs Committee. If we could get some more of them swung to approve now it would help achieve this vital shelter on Wednesday. Here is the link to the committee members:

http://www.gencourt.state.nh.us/house/committees/committeedetails.aspx?code=H09

And if you had any other capacity, it would help for your New Hampshire Senator to hear:

http://www.gencourt.state.nh.us/ns/whosmyleg/

And we don't want to leave the governor out:

http://www.governor.nh.gov/

And if you are further game you can attend the hearing at the capitol in the Hall of Representatives under the gold dome on this coming Wednesday the 17th of February 2010 anno domini. We'll have Lyme green ribbons and stickers for those who would like to show support at the hearing as we watch in the gallery and hand out literature in the hallway.

Now for those wanting further details, you'll see below pasted into this email a series of communications that I have sent around to representatives and newspapers and some other resources.

Also so you know bills go through a committee prior to going to the full house. This Health, Human Services, & Elderly Committee voted to send it to interim study. Often the full house just goes along with the committee so we have a bit of an uphill on this. We were successful though with keeping the thing from being killed or "inexpedient to legislate."

Hence my begging for your participation to call your representatives as well as forward this on to those you know who may join in.

You'll feel better for it and you will help those who are really significantly suffering.

Now for a swipe at explaining the bizarre assault. At least one source of opposition are insurance companies. They try to say that longer term, or chronic, Lyme does not exist. They don't have to pay for something that doesn't exist. Further they claim that treating for Lyme with long term antibiotics is dangerous. There are other diseases that treat with long term antibiotic treatment as a standard. Of course care has to be exercised but the point of all this is to allow for the doctor to care for their patient with "multiple standards of care" as they, the doctor find most optimal for we the patient.

One of those elemental freedoms that one would expect.

You can read more of my family's story below.

And here is the basic score sheet. Those trying to define long term Lyme out of existence are with or following IDSA or the Infectious Disease Society of America. Those who recognize the international body of knowledge with regards to long term Lyme and recognize that it can occur in a long term form are with or following the ILADS or The International Lyme and Associated Diseases Society. So IDSA are the bad guys and the ILADS are the good guys.

Here are the good guys website where you can get all kinds of information:

http://www.ilads.org/

One of the bits that is good are the guidelines.

If nothing else comes out of this missive, maybe if you or someone you know winds up with symptoms, the doctor might be asked to consider ilads guidelines.

See below for more.

Thanks so very much and please make Alexander Graham Bell proud of you!

Wishing all the best,

Tony

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As your word unfolds, it gives light,
and the simple understand.
Psalm 119:130

I plead for your participation in calling on your state representatives to pass into law on Wednesday HB 1326. Here is the meat of the bill: "No licensed physician may be subject to disciplinary action solely for prescribing, administering, or dispensing long-term antibiotic therapy for a patient clinically diagnosed with Lyme disease ..."

There is a bizarre situation necessitating the creation of this shelter to protect our physicians. I know of dozens of doctors across the country and a half dozen here in the State of New Hampshire that have had their businesses and careers threatened simply for recognizing this disease and treating it. Lyme Disease is fully challenging enough to combat without the doctors having to defend from insidious assault. This lack of elementary freedom in this land of freedom on such a vital topic is obviously something to correct and I beg for your assistance.

I am uniquely qualified to attest to the challenges of Lyme Disease. My wife and all three of my children have been diagnosed and treated for Lyme Disease. We have experienced the basic challenge in spades. We had long periods of time elapse prior to diagnosis which has allowed the disease go from something simple to a huge challenge. We have worked with doctors from New Hampshire, Connecticut, and New York and almost one in Massachusetts. The latter doctor was one of the many who didn't last too long in treating patients for Lyme Disease due to the bizarre assaults. We have had to wrestle with school and college systems to gain appropriate accommodations. We have wrestled with Insurance companies to gain appropriate coverages. We have wrestled with drug manufacturers with regards to pricing that did not reflect volume usage and so received thousands of dollars in donated drugs. We have agonized over the suffering of our family members with the symptoms of Lyme Disease in terms of pain, loss of mobility, loss of balance, lost time, confusion, chaos, isolation, lack of compassion, lack of respect, and lack of understanding. We have seen all these symptom vary widely daily. At one time we were paying three thousand dollars out of pocket per month for medications. Fortunately with some of the wrestling successes, that did not last long. Only by the grace of God we have weathered this storm and carry on. Two of the four who were diagnosed are still with significant challenges and two are doing pretty well thank God.

Lyme Disease when appropriately treated according to the ILADS guidelines can be truly eliminated when caught early on. If not caught and treated early, Lyme Disease can morph, and develop into a very smart combatant that can disguise itself as portions of our bodies which allows it to hide from our immune system. Lyme Disease also can cross into the otherwise super safe separate dedicated blood system that services our brain and spinal cord only. Once in this system the havoc that the Lyme bacteria can cause is without limits as it gets into the literal nerve center of our controls. Some of the symptoms are blindness, bells palsy, confusion, pains, numbness, decreased mental capacities, sadness, loss of mobility, degradation of joints, degradation of muscles, and death. It is vital to treat the stronger longer term Lyme also with the ILADS guidelines. I commend to you four resources, the ILADS website, the movie, "Under Our Skin," and the book, Healing Lyme by Stephen Burner, and the book, Cure Unknown by Pamela Weintraub.

This bizarre assault on doctors is something that causes additional unnecessary suffering amongst people who are suffering terribly with Lyme Disease. We have been successful in defeating the effort to kill this bill. It has been sent from committee to study but it appears that on Wednesday, 10 February 2010, the full New Hampshire House will vote on it. I beg for you and those who represent you to pass it on Wednesday the 10th and not let it get lost in committee and study. New Hampshire has the highest per capita incidence of this insidious disease. The suffering and chaos our citizens have endured is far more than enough. The time is now. Please participate. Thank you very much.

Begin forwarded message:
From: Anthony Dreux Fallon <tonyfallon@me.com>
Date: January 30, 2010 8:21:01 PM EST
To: David A.Bickford <david1@worldpath.net>
Subject: Re: HB 1326 Lyme Bill

Dave,

I do not know why they are restricted.

There is much conjecture.

I know how they are restricted.

It is by bullying. Threats of being fired, being hired only on condition of committing to not treat Long Term Lyme Disease, and efforts to have medical licenses suspended.

I know personally 4 doctors in New Hampshire that have been harassed.

If your read:

EVALUATION OF ANTIBIOTIC TREATMENT IN PATIENTS
WITH PERSISTENT SYMPTOMS OF LYME DISEASE:
AN ILADS POSITION PAPER
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Key words: Lyme disease, borreliosis, long-term antibiotics, tickborne diseases.

* The International Lyme and Associated Diseases Society (ILADS) is an international multidisciplinary medical organization of researchers and clinicians. ILADS has created an international forum to facilitate communication, scientific advancement and education of healthcare providers on the subject of Lyme and associated tickborne diseases. This paper was drafted by the authors and approved by the Board of Directors of ILADS. Members who contributed substantially to writing this position statement include:

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ABSTRACT

Background and Objective:

The history of Lyme disease has been characterized by intense controversy over the diagnosis and treatment of this spirochetal infection. A recent high-profile article by Klempner et al. [1] focused attention on the optimal antibiotic treatment for chronic Lyme disease. Because this research study has generated significant conflict and confusion in the medical community, we undertook a critical analysis of its methodology and conclusions.

Methods:

The International Lyme and Associated Diseases Society (ILADS) reviewed the article according to established standards of evidence-based medicine. Study design and scientific objectivity were analyzed in light of peer-reviewed medical literature on chronic Lyme disease and associated tickborne illnesses.

Results:

Numerous methodologic weaknesses are noteworthy in the study. These include inappropriate study design with respect to the antibiotic treatment regimen; inappropriate selection and inadequate randomization of study patients; failure to explain positive cerebrospinal fluid findings, and failure to report objective neurocognitive assessments; failure to assess coinfection status of study participants; exclusion of pertinent findings from the final report, with inadequate follow-up of study participants; and failure to recognize that spirochetal infection cannot be excluded without adequate culture techniques.

Conclusions:

The study by Klempner et al. contains a series of interrelated errors. It fails to achieve its stated goal of being a long-term, properly randomized, placebo-controlled treatment trial. The study appears to be scientifically invalid and risks harming patients if its flawed conclusions are accepted uncritically by physicians. In view of the uninterpretable results of this study, further research into the use of long-term antibiotic therapy for chronic Lyme disease is warranted.

INTRODUCTION

Lyme disease is a multi-system illness caused by infection with the spirochete *Borrelia burgdorferi*. Although Lyme disease was officially recognized in the United States in 1975 in the Connecticut town from which it derives its name, the disease had been discovered almost a century before in Europe, where the "bullseye" rash known as erythema migrans (EM) and the late stage rash and deformity of acrodermatitis chronicum atrophicans (ACA) were first recognized [2].

Rudolph Scrimenti first documented the EM rash in the United States in 1970, five years before the official labeling of Lyme disease [2]. Scrimenti noted a striking similarity between his patient's expanding ring-shaped skin lesion and the "erythema chronicum migrans" lesions he knew, in part, from the writings of Sven Hellerstrom [3]. Scrimenti published *Erythema chronicum migrans* in the July 1970 issue of the *Archives of Dermatology*, stating that this lesion was sometimes associated with significant neurologic symptoms [2]. Further, he postulated that spirochetes and/or rickettsiae caused the illness, which he thought was likely transmitted by ticks. His work established him as the actual discoverer of the disease that later came to be called Lyme disease. Yet both Scrimenti and Hellerstrom were openly ridiculed for their beliefs [4].

In the ensuing years, following Polly Murray's report in 1975 of an epidemic of multisystem illness including (but not limited to) arthritis in the now famous Connecticut town of Lyme [4], chronic and persistent sequellae of tick bites became common knowledge in both the scientific and lay communities. Those notably convinced included researchers such as Allen Steere, who in his early work wrote copiously on the subject of chronic neurologic and arthritic manifestations of Lyme disease, even in cases following antibiotic treatment [5]. In 1982, the spirochetal etiology of the disease was proven by Willy Burgdorfer [6], but this was only the beginning of what has since become a monumental task in understanding the pathogenesis of Lyme disease and its chronic manifestations, as outlined below.

A major problem with the diagnosis of Lyme disease stems from the variable results of serologic testing for its causative agent, *B. burgdorferi*. Indeed, well documented but seronegative Lyme disease has been widely reported in the medical literature [7–12], and the existence of seronegative infection is substantiated by the observation that the great majority of repeatedly infected deer remain seronegative for *B. burgdorferi* [13]. These observations raise doubt about the reliability of negative results using current Lyme disease tests, particularly when testing is aimed at the diagnosis of chronic as opposed to acute *B. burgdorferi* infections.

Just as seronegative but active Lyme disease has been documented in the scientific literature, so has active central nervous system (CNS) infection despite negative spinal fluid tests for *B. burgdorferi* [14,15]. Negative results are often obtained on cerebrospinal fluid (CSF) of known Lyme patients, including normal cell count and chemistry evaluations and absent Lyme antibody titers [14,15]. Consequently the absence of antibodies against *B. burgdorferi* in CSF cannot be relied on to rule out CNS infection with this organism. Given the foregoing, the diagnosis of *B. burgdorferi* infection should be made primarily on clinical grounds, with current serologies playing only supportive roles.

In addition to problems with diagnosis, it has been almost impossible to obtain a definition of cure for this illness due to inherent problems in culturing the organism. Without an easy method for culture, there has been no "gold standard" to assess treatment efficacy. Despite this uncertainty, some physicians insist that 30–day courses of antibiotic therapy are curative even for later stage Lyme disease. This belief persists despite seminal studies documenting that 30-day courses of antibiotics do not eradicate disseminated *B. burgdorferi* infection from mice, chimps and dogs [16–18]. Although animal data must be interpreted with caution, it is not surprising that many humans with late stage Lyme disease also are not cured of their symptoms with 30-day courses of antibiotics.

Indeed, there have been a number of peer reviewed publications demonstrating persistent infection with *B. burgdorferi* in humans despite multiple and extended courses of antibiotic therapy [19]. Persistent infection has been demonstrated repeatedly by both polymerase chain reaction (PCR) and histopathology [20–23]. Chronic infection has also been demonstrated by culture despite the well-known difficulties in harvesting *B. burgdorferi* from Lyme patients, and culture positivity has even been found in patients who are seronegative for the Lyme spirochete [24–30]. In light of such data, it would be illogical to assume that persistent symptoms in chronically ill Lyme disease patients are not related to active infection with *B. burgdorferi*. Ironically, and in direct opposition to the extensive body of published data, some researchers have attributed chronic symptoms compatible with Lyme disease to alternative vague diagnoses, such as "post-Lyme syndrome," fibromyalgia, or chronic fatigue syndrome [31,32]. The recent article by Klempner et al. [1] amplified the dispute between widely differing medical factions and prompted the current analysis.

METHODS

The International Lyme and Associated Diseases Society (ILADS), an international multi-specialty medical organization, reviewed the article by Klempner et al. [1] in an objective and didactic fashion. The review was accomplished using principles of evidence-based medicine [33]. Specifically, the study design, patient selection criteria, data reporting and outcomes analysis were all subjected to scrutiny. The conceptual framework of the study was also analyzed with reference to the published medical literature on chronic Lyme disease and associated tickborne illnesses, which includes more than 12,000 articles in the peer reviewed medical literature [19].

RESULTS

In reviewing the article by Klempner et al [1], it became apparent that there are multiple serious methodological flaws inherent in the fabric of the work. First and foremost is the initial contention that the study was intended to be a double blind, placebo-controlled trial of long-term antibiotic treatment for chronic Lyme disease patients of both seronegative and seropositive status. The authors used a treatment regimen consisting of one month of intravenous ceftriaxone at 2 gm daily followed by two months of oral doxycycline at 200 mg daily [1]. These antibiotics differ markedly in their mode of action and bioavailability, with no scientific evidence backing the assumption that their effect is additive or that the combination qualifies as "long-term" treatment. Consequently the trial amounted to a short-term ceftriaxone protocol for *re-treatment* of patients who had, without apparent success, experienced comparable treatment in the past, thereby undermining the principal objective of the study. Furthermore, the doxycycline dose used in the study (200 mg daily) was inadequate for CNS penetration [34]. Since the study population had neurocognitive symptoms, it is puzzling that the authors would use a medication dosage that achieves only marginal CNS concentration. To make matters worse, the acceptable medication compliance rate was 75%, reducing the doxycycline dose to sub-therapeutic levels. This was a regrettable oversight because enforcing a better compliance rate using the correct dosage would have been simple, inexpensive, and safe.

A related problem with the study derived from participants' prior antibiotic treatment. If this truly had been a long-term antibiotic treatment trial, one could have compared short and long term antibiotic treatment efficacy given the participants' prior "failure" with short-term antibiotics. However, since this was in reality a short-term ceftriaxone retreatment study, it fell prey to obvious selection bias in that many of the patients had already "failed" treatment with a short course of ceftriaxone, thus increasing the odds that they would do so again. This approach introduced significant selection bias into the study.

Selection bias was a key problem throughout the trial. For example, evaluated patients were excluded from participation if they tested positive by polymerase chain reaction (PCR) for the presence of *B. burgdorferi* DNA, barring from the study the very patients who may have been most likely to benefit from antibiotics. In addition, despite the fact that PCR negativity was obligatory for inclusion in the study population, PCR was then reported in the body of the work as if it were a new "finding". This may mislead readers to conclude that chronic Lyme disease patients do not frequently have intermittently positive PCR reactivity following treatment with antibiotics.

Criticism over the exclusion of PCR positives was voiced in published correspondence by Bransfield et al. [35], to which Weinstein and Klempner replied, "We screened over 1800 patients for this study, and no patient was excluded for this reason, since no patient was found to have a positive PCR assay or culture for borrelia—*a result that confirms the absence of evidence of active infection in this clinical syndrome*" [36]. However, the fact that the authors did not find even a single positive *B. burgdorferi* PCR out of the 1800 previously identified Lyme disease patients is in direct contrast to prevailing medical experience [20–30]. Although *B. burgdorferi* PCR has clinical disadvantages in sensitivity (see Discussion), it has been shown to be a valuable tool for the documentation of persistent infection in chronic Lyme disease patients [20–22,28].

Because the authors failed to find, even once, what other researchers have demonstrated repeatedly, doubt is raised as to the accuracy of their PCR methods. In sum, the statement by Klempner et al that they had confirmed the absence of active infection in this chronically ill population was patently inaccurate, as ample evidence has verified the persistence of *B. burgdorferi* infection in antibiotic-treated patients with chronic Lyme disease [20–30].

Additionally, randomization seems to have been insufficient in this research. Bransfield et al. state, "Furthermore, at baseline, the placebo and antibiotic groups appeared to have significantly different scores on the primary outcome measures. These observations suggest that randomization may have been inadequate, thereby invalidating the results of the study" [35]. Weinstein and Klempner respond, "The randomization protocol was adequate, since baseline values for the primary outcome measures in all patients were statistically equivalent in the placebo and antibiotic groups"[36]. However, the published data was in direct disagreement with their own statement because the authors report a number of significant pre-test differences between the placebo- and antibiotic-treated patients in the seronegative and seropositive groups. For example, among seropositive patients the baseline scores on the MOS Cognitive Scale were significantly worse in the antibiotic-treated cohort than in the placebo cohort. Furthermore, within the seronegative group of patients, the placebo cohort had significantly poorer baseline scores on the SF-36 Mental Component, the MOS Pain Scale and the Fibromyalgia Impact Questionaire than the antibiotic-treated cohort. These baseline differences could have biased the outcome of the study.

Weinstein and Klempner further stated, "Moreover, each patient served as his or her own control, since the clinical response was measured by calculating a change in health status for each patient" [35]. This argument is unconvincing because the authors did not address their reported pre-test differences. In addition, since the trial was conceived as a randomized, placebo-controlled study, analysis of covariance in the randomized groups would have been more appropriate than analysis of intrapatient variation to address the issue of inadequate patient randomization [37]. This type of analysis was apparently not performed.

While the study focused intensely on subjective neuropsychological testing, some noteworthy objective findings were reported succinctly without any discussion. For example, Klempner et al. found that over 25% of the enrollees had elevated CSF protein and that 8 had intrathecal production of *B. burgdorferi* antibodies. In patients with a history of well-documented Lyme disease and such CSF findings, these clinical parameters may be consistent with active neuroborreliosis. Instead, the authors focused on measurements of questionable utility in assessing chronic Lyme disease. Bransfield et al. criticized the authors in this regard by writing, "The neuropsychological scales used in the study were insufficient to assess the cognitive impairments in executive functioning and the psychiatric dysfunctions that are seen in patients with persistent Lyme disease. The SF-36 is a subjective assessment scale, based on the patient's self-perception. There was a paucity of objective measures to assess the patient's status"[35]. Weinstein and Klempner replied that the enrollees were given an "extensive battery of neurocognitive tests in addition to the SF-36. A forthcoming analysis of these data should help to demonstrate any cognitive impairment, should it exist" [36]. Yet the question arises as to

why this "extensive battery" of neurocognitive tests was not discussed in this paper, where it might have aided in the serial analysis of the patients' neurocognitive dysfunction during antibiotic treatment.

Such omission raises the question as to what other data collected during this study was excluded from the formal report. For example, Klempner publicly alluded to his testing for CSF matrix metalloproteinases in these patients (Klempner MS, 11th Annual Diseases of Summer Conference, South County Hospital, Wakefield, RI, 2001), but this was not reported in the study. Since Klempner previously published on the presence of these markers both *in vitro* and *in vivo* in active neuroborreliosis [38,39], we anticipated that the paper might have included this important objective data. Had it been revealed, it could have provided additional clues regarding the presence or absence of active neuroborreliosis, and thus might have added significantly to the study.

A final problem with the study's data analysis is the exclusion of possible Jarisch-Herxheimer reactions. As in syphilis, another spirochetal infection, Lyme disease patients frequently experience this symptom intensification upon initiation of antibiotic therapy [40–42], yet this was not evaluated. Failure to discuss this symptom complex is a serious oversight, since any assessment of interval change in patient status could not be conducted properly without consideration of such a common phenomenon. Indeed, for patients with active *B. burgdorferi* infection, worsening symptoms due to Jarisch-Herxheimer reactions potentially could have been troublesome enough to prompt their withdrawal from the study unless this complication had been discussed with them in advance.

DISCUSSION

The methodologic deficits described above reflect the fact that the complexities of *B. burgdorferi* pathogenesis were not fully taken into consideration by Klempner et al. As a result, the authors ignored the critical context for exploring diagnostic factors and treatment responses in chronic Lyme disease. For example, *B. burgdorferi* has the ability to survive in divergent conditions of mammals and ticks by existing in a variety of forms that are ultrastructurally and metabolically distinct. Even in the tick, altered morphologic forms of *B. burgdorferi* are present [43], but in the mammal, selective pressure from mammalian immune surveillance results in these altered forms becoming more common. These "host adapted" forms generally display altered morphology to varying degrees and are referred to collectively as L-forms or spheroplasts. *B. burgdorferi* spheroplasts, of which cystic forms and granules are sub-types, have been extensively documented *in vitro* and *in vivo* [44–53], both extracellularly and intracellularly [27,47,54–57]. Their ability to revert from host-adapted forms back to helical forms under appropriate conditions has been demonstrated *in vitro* [47,58,59].

To the uninitiated, it may be tempting to infer that *B. burgdorferi* cystic forms are degenerative bacterial fragments. This is not the case, since researchers have demonstrated protein synthesis requirements for spirochetal conversion into the spheroplast form [44]. Indeed, it has been unequivocally proven that *B. burgdorferi* cystic forms are virulent and infectious. Their infectivity, survival under extreme environmental conditions, and ability to revert back to helical forms *in vivo* have all been demonstrated by inoculation of *B. burgdorferi* cysts into mice and subsequent recovery of helical spirochetes from the animals [60]. As such, host-adapted forms of *B. burgdorferi* are considered to be major factors in the relapsing and persistent nature of Lyme disease [61–63].

Just as *B. burgdorferi* spheroplasts have altered metabolic requirements for growth, so too, do they have unique antibiotic sensitivities, altered surface protein expression, dramatically reduced surface area presented for immune surveillance, and the ability to cause multiple potential problems for PCR analysis. All of the foregoing helps to explain observations of antibiotic resistance, seronegativity, and even frequent PCR negativity in active disease [51,54,59,63,64]. The failure to address the complexities of the borrelial life cycle in the work by Klempner et al. is a serious error. For example, the fact that cystic forms demonstrate sensitivity to metronidazole while their helical kin are resistant, illustrates the point that *B. burgdorferi* spheroplasts have altered antibiotic resistance [65]. Attention to these forms during the initial study design might have resulted in different treatment decisions, with consideration that a cell wall-attacking cephalosporin may not have been the ideal antibiotic choice for treatment of cell wall-deficient organisms in patients with late-stage Lyme disease.

In addition, had the authors addressed the intracellularity of *B. burgdorferi*, this might have broadened their choices of antibiotic therapy. Although the utility of ceftriaxone for Lyme disease has been documented, it has been similarly documented that this agent frequently does not fully eradicate human *B. burgdorferi* infections [19]. Cephalosporins do not achieve intracellular penetration, a fact that may partially explain well-known treatment failures associated with late stage Lyme disease. Indeed, *B. burgdorferi* has been documented within a variety of cell types, including but not limited to endothelium, fibroblasts, lymphocytes, macrophages, keratinocytes and synovial cells [17,51,54,66–70]. These findings are critically important since chronic infections are highly dependent on intracellular asylum as a mode of persistence, and localization within eukaryotic cells protects *B. burgdorferi* from antibiotics [71,72]. It is particularly surprising that the lead author agreed to use ceftriaxone in this study, since he previously authored a paper on the fibroblast-mediated protection of *B. burgdorferi in vitro* from concentrations of ceftriaxone achieved *in vivo* for the treatment of Lyme disease [71].

Another conceptual oversight in this study was the lack of consideration in the body of the manuscript of co-infections commonly found in Lyme disease patients. In addition to *B. burgdorferi*, Ixodes ticks transmit other pathogens that may have infected the study patients, such as *Babesia*, *Ehrlichia* and *Bartonella* species [73–80]. These tickborne coinfections apparently were not considered in the evaluation of patients but could well have been clinically relevant and affected outcomes in the study, since they occur in approximately 10% to 66% of Lyme disease patients [73–78]. As with most tickborne illness, the clinical spectrum of these coinfections spans sub-clinical to life threatening presentations [75,76], and they are underdiagnosed in all age groups [73].

Despite the severity of illness documented in this study's chronic Lyme disease patients, and the fact that neither ceftriaxone nor doxycycline effectively treats certain coinfections, this potential drawback was not mentioned in the body of the paper. Furthermore, aside from non-spirochetal co-infections that can be tested for, there are other tickborne spirochetal infections for which there is no commonly available testing [81,82]. These unknowns also should have been mentioned in the body of the study since it is not clear to what extent they may cause or prolong illness or to what extent they are amenable to antibiotic therapy.

In summary, the methodologic problems of the study reflect an apparently inadequate appreciation of Lyme disease pathogenesis and persistence in patients with chronic symptoms of tickborne disease.

CONCLUSIONS

In our analysis, the study by Klempner et al. fell prey to a series of interrelated errors. The study began by missing its initial design goal of being a long-term, properly randomized, placebo-controlled antibiotic treatment trial for patients with chronic Lyme disease, simply because the treatment provided was not long-term. Many methodologic and conceptual aspects of the work were flawed, resulting in patient selection bias, suboptimal antibiotic treatment regimens, faulty analysis and/or exclusion of data, and disregard for *B. burgdorferi* microbiology and pathogenesis.

Based on its many errors, much of the article by Klempner et al. is, in our opinion, scientifically invalid and risks harming patients if it is accepted uncritically by physicians who may not have the time or the expertise to analyze the work. Indeed, a majority of medical practitioners may, after reading this paper, inappropriately withhold treatment from patients with persistent Lyme disease [83]. This would be especially troubling since other peer reviewed medical research demonstrates that extended treatment with months of the correct choice of antibiotic therapies can be remarkably beneficial for patients with late-stage Lyme disease [84–86]. Certainly, long-term antibiotic treatment is medically accepted and approved for other chronic infectious diseases such as tuberculosis and leprosy [87–89]. We hope that future studies of long-term treatment of Lyme disease will be designed, implemented and analyzed in a more appropriate manner.

AUTHOR CONTRIBUTIONS

Dr Phillips wrote the initial manuscript, researched the initial references, initially coordinated the project and participated in many editing reviews. Dr Bransfield wrote the initial outline, wrote and researched sections of the article, participated in many editing reviews and coordinated completion of the article. Dr Sherr wrote and researched sections of the article, served as a liaison to the ILADS board and participated in many editing reviews. Dr Brand wrote and researched a section of the article related to research design and participated in some reviews. Dr Smith wrote sections of the article, participated in many editing reviews, rewrote one of the revisions and checked for the accuracy of the references. Kathleen Dickson wrote sections and participated in editing reviews. Dr Stricker wrote a section on the study protocol, edited the section on coinfections, contributed assistance with the references, participated in final review of the manuscript and coordinated completion and submission of the article.

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you can get a feel for the disagreement between the professionals.

As to the why, which I don't focus much on, one of the many conjectures is that insurance companies are trying to duck payment. There are some cloak and dagger conjectures too but I don't focus on that.

The sales pitch of those seeking to limit care options is twofold. They try to define Long Term Lyme Disease out of existence and then try to say that treating Long Term Lyme Disease is dangerous.

Dave, I attest and assure you after seeking for 20 years to find what was wrong with my wife after testing for MS, Lupis, and on and on and on and then getting a proper diagnosis and a proper treatment and watching her improvement, and to have similar results with all three of our children,,,,,, the dang horrific disease does exist in a long term form and the long term treatments are much safer than the travesties of allowing this terrible bacteria to bloom and become more enabled, entrenched, and morphed into all its various areas and modes. Yeah I know that was a run on.

To battle this disease is enough.

To have to play hide and seek and drive to Connecticut or Manhattan for care is beyond the beyond.

Please if there is anything you can do with this one in talking to the committee members or anything else, I would so much appreciate it. It has had a devastating impact on our family with 4 members affected. I would be very happy to discuss further and am home this evening.

home 603 269 2298
business 603 269 3206
cell 603 534 0220

Thanks for your service!

I really appreciate it David,

Tony

On Jan 30, 2010, at 4:50 PM, David A.Bickford wrote:
Tony,

I had no idea doctors were restricted from long term treatment of any disease. Why are they restricted?

Rep. David A. Bickford
183 Brackett Road
New Durham, NH 03855
(603)859-7899
david1@worldpath.net
----- Original Message -----
From: Anthony Dreux Fallon
To: david1@worldpath.net
Sent: Saturday, January 30, 2010 12:00 PM
Subject: HB 1326 Lyme Bill

Dear David,

Please consider this topic and talk with other reps particularly those on **HEALTH, HUMAN SERVICES & ELDERLY AFFAIRS**

Thanks,

Tony

Gentles:

I ask you again to vote in a positive, care filled, and responsible manner for the Lyme Bill, HB 1326, to go to the floor.

I have heard that there is concern due to idsa claims that Lyme cannot occur in long term, or chronic form and their questioning the safety of treatment protocol.

I attest to you that in watching and caring for my wife and children whom have all had Lyme Disease that after long searches for the source of suffering, once we found that Lyme was the source, the long term treatment of antibiotics, both iv and oral, produced significant relief. So in my experience as a husband and father it does exist and the ilads recommended protocol of long term antibiotics is beneficial.

I plead with you to not go weak in the knees with this due to controversy. Why such organizations would work to try to counter what we have found to be the case, and work for relief, in multiple family members is bizarre.

I also plead with you to see that this is not simply a case for non professionals versus professionals. There is an eloquent, dedicated, brilliant, and brave body of professionals battling both this horrific wily disease and this bizarre misinformation campaign. The key source for information from the white hat professionals on this topic is http://ilads.org wherein you can see a wealth of information and links to other sites. I also have attached a paper where these white hat professionals take on the dark side in professional speak terms.

And I plead again with you to recognize that the devastation caused by this disease on a family and a person in a myriad of aspects of pain, confusion, suffering, debilitation, numbness, blindness, cognitive loss, changing symptoms, finances, career loss, education loss, friend loss, and chaos is more than enough for the citizens of New Hampshire to deal with. To further burden those so affected with this bizarre misinformed assault on them and their health care providers, is a grave injustice.

I remind you that the states of Rhode Island and Connecticut have done the right thing to protect the backs of their constituents and their health care providers and removed this unnecessary, unjust, terrible burden. I plead with you to follow suit.

The bizarre claim of danger of treatment is in itself dangerous as it enables unnecessary full blooming of this dastardly debilitating disease. If properly treated early on it can be eliminated. If left it goes through grows into awful capacities and varieties.

This needs to be brought out to the floor and we need to build a roof and walls to go with it so as to protect our doctors from these bizarre assaults so they can help us fight this dangerous disease with all arrows in the quiver.

I would be delighted to discuss this further with you.

Thank you again for your service.

Courage,

Tony

Planned testimony to the Health, Human Services and Elderly Affairs Committee that I wound up just submitting in written form:

I come to you as a father of three children who have been treated with Lyme Disease and a husband whose wife has been treated. I have spend tens of thousands of dollars and driven as many miles desperately trying to assist over these last years that we have gotten diagnoses and gotten with trying to treat. I have driven to appointments in Orange & Stamford, Connecticut, Manhattan, and a couple of places in New Hampshire hundreds of times. Once I was looking at $3000 per month out of pocket on top of the $1000 per month premium. I have negotiated and wrestled with Insurance Companies and Drug Manufacturers with some success.

I thank you for your service to the State of New Hampshire. It is essential and appreciated. Please know that chronic Lyme is as real as the limes in front of you despite what the yellow backed lemons are saying. (I was going to use limes for props in front of you)

With what I have lived with regards to this topic, I assure you with all my being that Lyme Disease does exist, that Lyme Disease does exist in a chronic form, that it is an awful disease with rolling changing symptoms that are debilitating, and that we need to have doctors backs in treating this. This last point is where we are asking for your participation here, to protect the doctors. Trying to discern and determine what is the current best treatment given the current morphing of the Lyme is totally enough for a doctor to do. To have this occur in an atmosphere of concern of hospital privileges and medical licenses being pulled is over the top terrible. I pray for your help and participation in more optimally organizing the response to Lyme with proper rules to protect doctors in their care.

Top Ten Reasons to Pass HB 1326:

1. New Hampshire has the highest per capita incidence of Lyme Disease in the USA. Rockingham and Strafford Hillsboro Counties have the highest incidence of Lyme Disease in NH.

2. Lyme Disease is easy to treat if caught early, but difficult and complex to treat if found late.

3. Lyme Disease testing is seriously flawed. It is based on having a healthy immune response to proteins found in the bacteria. Sick people frequently don't have a healthy immune response.

4. The Infectious Disease Society of America (IDSA) is a powerful lobby that has set guidelines for treating Lyme Disease based on a limited body of science. It's lyme disease treatment guidelines committee has been charged guilty in a class action suit posed by CT Attorney General Bumenthal. 9 of the 12 committee members were found to have financial and business conflicts of interest.

5. The International Lyme and Associated Diseases Society (ILADS) is a relatively small group of dedicated Drs. who have studied a large body of science and have a set of treatment guidelines that recognizes chronic lyme disease and is vastly different form the IDSA's point of view.

6. When more than one standard of care exists, the critical question becomes "who" decides the appropriate course of treatment for the patient. Under the medical ethical principle of autonomy, the treatment decision belongs to the patient! Hence, the American Medical Association requires that the physician disclose and discuss with the patient not only the risks and benefits of the proposed treatment, but also the risks and benefits of available alternative treatments. (Lyme Disease: Two Standards of Care, Johnson, L, www.harp.org/Twostandardsofcare.htm)

7. Many NH Drs. do not know that there are two standards of care for Lyme Disease. Conversely, many NH Drs. have been told they may not treat by ILADS guidelines for fear of loosing hospital affiliations. The IDSA, and the insurance industry would like lyme disease treatment to be quick and easy. Reality shows that Lyme disease is complicated and can be chronic.

8. Lyme Disease can mimic CFS, fibromyagia, arthritis, heart disease, asthma, ALS, MS, IBS, ADHD, autism, Parkinson's, Alzheimer's, Lupus and more.

9.Lyme disease can cause temporary and permanent memory problems, motor problems, and cognitive problems. Lyme disease can cause seizure disorders, Bone muscle and nerve pain and changes.

10. Many people in NH have lost their livelihoods from Lyme Disease. But worse than that are the numbers of people who died before getting proper treatment for a little tick bite!

We need this bill now! It does not need to go to interim study. The sooner it passes, the sooner we get better Lyme Disease treatment options for the citizens of New Hampshire!

This list was written by Erin Fallon. I have chronic lyme disease as do all three of my children. It has been assumed by more than one Dr. that my children aquired lyme in the womb, as the bacterum is known to pass through cord blood. Currently two of us are on long term antibiotic treatment after a relapse. Two of us have permanent neurologic damage from the disease. After 4 yrs of trying to return to my pervious carreer in the healthcare field, I have gone into retirement at age 50 on SSDI.

Erin Fallon,501 Barn Door Gap, Strafford, NH 03884
home:603-269-2298 cell:603-534-0229

Please contact me with questions!

February 14, 2010

UNDERSTANDING THE HISTORY OF THE LYME DISEASE TREATMENT CONTROVERSY

Relating to **HB 1326** - Please pass this bill NOW!

Lyme Disease can be ***FATAL*** if not treated.

According to the Lyme disease documentary film 'Under Our Skin', this is a chronological summary of the issues surrounding the treatment of Lyme disease.

1. In 1980, the federal government passed a law allowing doctors and medical researchers to patent their findings. This meant that information was no longer shared, but patented and hoarded in hopes of future profits. This caused the problem that most doctors today are not 'Lyme literate' and do not understand the symptoms, diagnosis and treatment of Lyme disease.
2. In 1981, the ***cause*** of Lyme disease was discovered, which could then be patented. The condition was given its name of 'Lyme' in the mid 1970's but the cause was not known at that time. The causative agent, 'Borrelia Burgdorferi' or *Bb* was discovered to be the cause of Lyme disease. It is a spirochete (cork screw) structure that is transmitted from a tick bite. It can alter into two other structures when stressed by the immune system or by antibiotics, forming an L shape, or forming a cyst. It is a smart bacteria that can mimic the body and hide from treatment. It can be persistent in the body and cause relapse.
3. Next, the 14 member panel of the Infectious Disease Society of America (IDSA) wrote a devastating recommendation for the treatment of Lyme disease. The panel members were supposed to meet to discuss the recommendations. This did not happen. The chairman, Dr. Wormser, took over the task and along with a select few, wrote the recommendations largely based on their own publications. They did not allow input from other panel members and did not take into consideration the massive amount of other studies recommending long term antibiotic treatment.
4. WHY? In an investigation of the 14 member panel by the governor of Connecticut, it was discovered that 9 of the 14 panelist who write the treatment recommendations, have conflicts of interest. They have ties to insurance companies and/or other for profit companies with a great interest in suppressing the treatment of Lyme disease patients.
5. The IDSA recommendations state there is no such thing as Chronic Lyme Disease. It states that Lyme Disease is easy to diagnose, easy to treat, and the patients with long term symptoms are experiencing 'Post Lyme Syndrome' which is symptoms due to normal aging or damage to their systems from the Lyme disease. ALL OF THIS IS FALSE.
6. Lyme disease can mimic a lot of other diseases so it is very hard to diagnose. The symptoms vary from person to person as well. A person can have different symptoms over time. Long term chronic Lyme disease does exist and has been successfully treated with long term antibiotics. Children and adults have been successfully treated with long term antibiotics. Children who suffer from chronic Lyme disease do not have aging symptoms, it is the Lyme disease!
7. Some say that there are risks with long term antibiotics; however, there are many other diseases that are regularly treated with long term antibiotics. This is accepted medical practice.
8. A doctor, Alan B. MacDonald, testified in the film that in his research, he discovered the Lyme disease 'Biofilm'. This proves that chronic Lyme does exist, it is hard to treat, and is capable of relapse, as this is the definition of a Biofilm.
9. All over the USA, Lyme patients are struggling to get the treatment they need, due to this political environment.
10. Doctors who treat Lyme patients have been harassed by other doctors who are not 'Lyme literate' and by insurance companies. Doctors have had to go before the medical review board for treating Lyme patients with long term antibiotics and have had their license suspended because they did not follow the IDSA recommendations. The bulk of the complaints are filed by insurance companies who don't want to pay for the long term treatment. NH doctors have been harassed and even required NOT to treat patients with Lyme disease in order to be hired. The doctors risk losing their ability to bill insurance companies and thereby lose their practice.

Please refer to the International Lyme and Associated Diseases Society (ILADS) for up to date research and recommendations for the treatment of Lyme disease at http://www.ilads.org/.

HB 1326 in essence states: **"No licensed physician may be subject to disciplinary action solely for prescribing, administering, or dispensing long-term antibiotic therapy for a patient clinically diagnosed with Lyme disease ..."**

PLEASE PASS HB 1326. Do not put it into interim study. NH residents with Lyme disease need medical attention now, not a year from now. Our doctors need to be able to treat Lyme without the harassment they are currently receiving. We need more doctors in NH who are willing and able to treat Lyme patients.

Written by Arlene Stoppe, 85 Leavitt Hill Road, Ashland, NH 03217, Cell: 603-481-0374, Home: 603-968-4478

Anthony Dreux Fallon
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As your word unfolds, it gives light,
and the simple understand.
Psalm 119:130

Attachment 13

Apr 26, 2010

EXECUTIVE DEPARTMENTS AND ADMINISTRATION
House Bill 1326
AN ACT relative to the use of long-term antibiotics for the treatment of Lyme disease
Public Hearing: 04/26/2010 at 01:00 PM LOB 206-208

My ordeal began in 1996 when at that time the Lahey Clinic diagnosed my exhaustion as Chronic Fatigue Syndrome. I chased an unresolved fatigue for twelve years while ping ponged through the medical community never receiving a Lyme test. I was evaluated for a possible mitochondrial disorder at Tufts New England Medical Center as my energy production was extremely impaired. Over that twelve year period I spent in excess of sixty thousand dollars trying to figure out what was wrong with my health. By the time I was properly tested (November 2008) through a Western blot Lyme blood test, I was bedridden, on oxygen and completely disabled.

I am fortunate to have a Lyme Literate Infectious Disease Specialist who treats late stage or chronic Lyme disease with long term antibiotics. My long standing untreated infection affected my heart, liver, joints/muscles and cognitive function which ended a twenty five year High Tech sales career. After sixteen months on antibiotic therapy I no longer require oxygen and walk twenty minutes per day. I have a long road to recovery at this point due to the length of time without proper diagnosis but I honestly don't know if I would be here today if Lyme specific antibiotic treatment was not prescribed long term.

My wife has had joint pain for five years diagnosed as Fibromyalgia. Her pain was especially bothersome in both knees to the point where walking up stairs was extremely uncomfortable. We attempted to treat her achy joints with supplements but experienced only limited success. She was often fatigued after work and fell asleep shortly after dinner. A Western blot Lyme blood test revealed antibodies to Lyme disease identifying an active infection. She has been on long term antibiotics (11 months) for chronic Lyme disease and now her so-called "Fibromyalgia" is non existent. I would like to point out that her Dartmouth Hitchcock primary care physician who is <u>not</u> Lyme literate refused to order the more specific Western blot test after her Elisa Lyme test came back negative. The Elisa is less than 65% accurate so those physicians who are unaware of the testing flaws usually provide an inaccurate diagnosis.

Our daughter has always been a happy child with exceptional grades so when we experienced a serious change in mood we knew something was drastically wrong. She became short fused, angry or irritable all the time with mood swings/depression and developed a combatant behavior. These symptoms as we have since learned are a result of Psychiatric Lyme Disease. Once again, a Western blot Lyme blood test revealed antibodies to Lyme disease identifying an active ongoing infection. She is the only family member who actually had a deer tick imbedded in the abdomen but she did not develop the rash. Long term antibiotics for chronic Lyme disease has given us back our happy daughter who is more patient now with no "freak outs" as we called them otherwise known as Lyme rage.

My daughter's primary care physician who is not Lyme literate called to inform her that she didn't have Lyme disease based on lab results alone without seeing her or considering clinical symptoms whatsoever. That in my opinion is medical malpractice.

Our family is being treated by a Lyme literate doctor who we are grateful. Please support House Bill 1326 intended to protect doctors **(and we should include nurse practitioners)** who specialize in treating Lyme disease so we don't lose the limited valuable resource we currently have available.
Lyme disease is only controversial until you experience it yourself.

In closing I would like to comment that the medical professionals here today in opposition of house Bill 1326 most likely have never treated a late stage Lyme patient. I ask that you keep that in mind when listening to the testimony.

Respectfully,

Carl W Tuttle

Carl W Tuttle
33 David Dr
Hudson, NH 03051
(603) 479-4927

My Late Stage Lyme symptoms were staring everyone in the face (cognitive decline, debilitating exhaustion, joint pain) but the lack of knowledge of the disease and misdiagnosis left me disabled.

Describing the difficulties our family has faced and the seriousness of the disease is important, pointing out how we got here is equally important. We have learned through our own personal experiences that we have a medical community uneducated in the diagnosis and treatment of Lyme disease in the absence of that bulls-eye rash. None of our family members developed the rash.

We have a two tier system of testing for Lyme disease, the Elisa test and Western Blot. The Lyme literate doctors don't bother with the Elisa because it's unreliable. You will be denied the more sensitive Western blot when the Elisa test comes back negative as was the case with my wife.

The Western Blot has problems of its own. Strict criteria were created in 1994 for surveillance of Lyme disease and only those patients who met the strict case definition were reported to the CDC. So if you did not meet those criteria your Western blot stated NEGATIVE. In February of 2005 the CDC issued a caution regarding testing for Lyme disease: (I will read this so as not to misquote)

Health-care providers are reminded that a diagnosis of Lyme disease should be made after evaluation of a patient's clinical presentation and risk for exposure to infected ticks, and, if indicated, after the use of validated laboratory tests.

In 2008 the CDC updated its Lyme Case Definition stating the following:

"This surveillance case definition was developed for national reporting of Lyme disease; it is not intended to be used in clinical diagnosis"

I have a copy of my wife's Western blot here for your review. You will see the words NEGATIVE on the lab results. My daughter's Western blot states negative as well.

The lab report is missing the disclaimer that a diagnosis of Lyme disease should be made after evaluation of a patient's clinical presentation and risk for exposure to infected ticks. It's also missing the fact that the case definition was strictly developed for national reporting of Lyme disease and is not intended to be used in clinical diagnosis. I filed a complaint with the NH Attorney General's office against Quest Diagnostics for misleading the physician by not including the disclaimer. Of course the primary care physician sees NEGATIVE on the report so you don't have Lyme disease.

Lyme literate Infectious Disease Specialists recognize that it is not necessary to meet the case definition in order to diagnose Lyme disease.

Imagine designing a screening test where negative results are seen 95% of the time? Insurance companies are eager to deny coverage based on those negative lab results.

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SPECIMEN INFORMATION
SPECIMEN: WC922124A
REQUISITION: 2312687

COLLECTED: NOT GIVEN
RECEIVED: 04/09/2009 01:45 ET
REPORTED: 04/16/2009 08:12 ET

PATIENT INFORMATION
TUTTLE,JANET

DOB: 12/10/1956 AGE: 52
GENDER: FASTING: U

ID:
PHONE: 603.886.6462

REPORT STATUS FINAL REPRINT

ORDERING PHYSICIAN
DONTA,SAMUEL

CLIENT INFORMATION
NE66007401 CA000159
DONTA INFECTIOUS DISEASES

PO BOX 944
FALMOUTH, MA 02541-0944

Test Name	In Range	Out of Range	Reference Range	Lab
LYME DISEASE ANTIBODIES (IGG, IGM) WESTERN BLOT				QCA
LYME DISEASE AB (IGG) WB	NEGATIVE		NEGATIVE	
18 KD (IGG) BAND	NON-REACTIVE			
23 KD (IGG) BAND	NON-REACTIVE			
28 KD (IGG) BAND	NON-REACTIVE			
30 KD (IGG) BAND	NON-REACTIVE			
39 KD (IGG) BAND	NON-REACTIVE			
* 41 KD (IGG) BAND		REACTIVE		
45 KD (IGG) BAND	NON-REACTIVE			
58 KD (IGG) BAND	NON-REACTIVE			
66 KD (IGG) BAND	NON-REACTIVE			
93 KD (IGG) BAND	NON-REACTIVE			

* 1 single band

NEGATIVE For Surveillance purposes only!

IGG WESTERN BLOTS WHICH HAVE 5 (OR MORE) OF THE 10 SIGNIFICANT BANDS ARE CONSIDERED POSITIVE FOR SPECIFIC ANTIBODY TO B. BURGDORFERI. (PROCEEDINGS OF THE 2ND CONF. ON LYME DISEASE, DEARBORN, MI, 1994.)

Test Name	In Range	Out of Range	Reference Range	Lab
LYME DISEASE AB (IGM) WB	NEGATIVE		NEGATIVE	
* 23 KD (IGM) BAND		REACTIVE		
39 KD (IGM) BAND	NON-REACTIVE			
41 KD (IGM) BAND	NON-REACTIVE			

* 1 single band

IGM WESTERN BLOTS WHICH HAVE 2 (OR MORE) OF THE 3 SIGNIFICANT BANDS ARE CONSIDERED POSITIVE FOR SPECIFIC ANTIBODY TO B. BURGDORFERI. (PROCEEDINGS OF THE 2ND CONF. ON LYME DISEASE, DEARBORN, MI, 1994.)

HARD COPY TO FOLLOW

Fifteen year old conference

Page 1 - Continued on Page 2

04/20/09 13:15 [illegible] 1/1

No disclaimer reminding the physician that a diagnosis of Lyme should be made after evaluation of the patients clinical presentation.

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COLLECTED: NOT GIVEN
REPORTED: 04/16/2009 08:12 ET

PATIENT INFORMATION
TUTTLE,JANET

DOB: 12/10/1956 AGE: 52
GENDER: FASTING: U

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Laboratory Director: SALIM E KABAWAT, CLIA: 22D0650288

NO COLLECTION DATE RECEIVED. WE HAVE USED
THE DATE THE SPECIMEN WAS RECEIVED BY THIS
LABORATORY AS THE COLLECTION DATE. IF THIS
IS INCORRECT, PLEASE CONTACT CLIENT SERVICES.
PHONE NUMBER: 1-866-697-8378

Attachment 14

Julie Hall, Kensington, New Hampshire

Hi. My name is Julie Hall. I am here because I was infected by Lyme Disease, as were three of my children, in the last six years. We live in Rockingham County, which has the highest incidence of Lyme Disease in the state and where more than 50 percent of the black-legged ticks carry the bacteria that causes Lyme. It's a scary place to live right now.

It's my oldest son, Tucker, whose story I want to tell. Tucker who was the straight A student, the All-Star Baseball player—first, third and pitcher, thank you - the guy with a ready smile and a can-do attitude.

Tucker, who was diagnosed with Lyme in 2004 and, two years ago had to be carried to the bathroom, missed six months of school, ended up in a wheelchair because of joint pain, and had numerous invasive procedures because doctors in New Hampshire and Boston refused to believe that his symptoms might be related to his earlier Lyme diagnosis. Tucker, who is healed and well today and no longer needs treatment because a Connecticut doctor was courageous enough to treat his symptoms despite threats to his own medical license for doing so.

You see, Tucker was originally treated according to the Infectious Disease Guidelines, which state that two to four weeks of antibiotics is effective in eradicating Lyme. My doctor at the time did not inform me that there was another set of guidelines; he did not give me the option to choose how best to treat my son. ~~I no~~w realize that cancer patients are given more choices in their care than Lyme ~~patie~~nts.

That winter Tucker became symptomatic again. He was put on a course of 12 weeks of antibiotics, as our nurse practitioner had done some research, and now recognized that the Lyme bacteria had not been eradicated with the "standard treatment." He was, she said, "undertreated" the first time. She was right, but by then it was too late.

Tucker developed symptoms again in 2007 during football practice. Stomach pain. Intestinal pain. Headaches. Dizziness. Our doctor thought it was a flu. But he didn't get over it. Then he thought it was stress. Maybe celiac. When he didn't get better after months, he wondered about depression. I kept asking about Lyme. Could it be Lyme again? No, he said. It doesn't present this way according to the guidelines I follow. Can we treat prophelactically to see if he responds to antibiotics, I asked? No, he said, indicating the seriousness of antibiotic resistance (this from a doctor who would write me a script for penicillin if I called to say Tucker had spots in his throat). He wrote in Tucker's chart, "mom needs to stop the charade that this is Lyme."

We went to the Infectious Disease specialists in Boston. We went to the homeopaths. We went to the psychologists. "Could it be Lyme," I asked out loud, over and over again. Not according to the IDSA guidelines, they said. We took him to Rheumatologists, Gastrointologists, and any other "ist" you can find. He had his appendix out. Maybe that would help. He had exploratory abdominal surgery to rule out cancer. When he couldn't walk anymore because of chronic knee and ankle pain and could barely pick his head off the pillow, a new New Hampshire doctor said, now this looks like Lyme. A specialty lab confirmed the diagnosis.

He put him on a short course of antibiotics. When Tucker did not respond, he shook his head. He explained that Tucker probably needed long-term treatment and, most likely, IV treatment. But he would not treat him. Sadly, he said, he could lose his license. I was stunned. Where could I go?

I was referred to one of the state's few Lyme specialists, Dr. McNeel, who had treated thousands of Granite State patients. Unfortunately, he was closing his practice in part, he said, because of the subtle pressure from the medical community for his use of long-term antibiotics to treat chronic Lyme disease. Could he recommend anyone, I asked? He explained that most New Hampshire doctors fear using long-term antibiotics because they have seen their colleagues around the country lose their license. He suggested we take Tucker out of state.

So, we drove to Connecticut to meet with Dr. Jones, a world-renowned Lyme specialist who has treated more than 10,000 cases of pediatric Lyme, 90 percent of them successfully. Dr. Jones, who is one of many doctors around the country who has been in court fighting to retain his medical license for years because the medical board and Infectious Disease Society (IDSA) is so intent on prohibiting doctors from treating according to any guidelines other than their own. Dr. Jones who continues to practice at 80 years old because he is dedicated to saving lives and has nothing to lose if the medical board finally takes his license. And, more importantly, because he knows the ILADS guidelines work.

Dr. Jones spent four hours performing a clinical evaluation that day. "You're fix-able," he declared to Tucker. And my son smiled for the first time in months. He carefully explained the difference between IDSA guidelines and ILADS guidelines, and the medical research backing both. He explained how the IDSA studies were seriously flawed & had been interpreted quite differently by ILADS experts.

CT-scans and biopsies indicated that the spirochetes had impacted my son's brain, his organs, etc. They had been festering in his body for years, and he was one sick boy. Together, we decided to begin what would become two years of aggressive oral and IV antibiotics.

That treatment saved my son's life. Today, Tucker he is a healthy freshman in high school. He is preparing for baseball season, competed on the Varsity Ski Team, does well in school, and speaks to kids infected with Lyme from around the country.

Tucker has not been on antibiotics for a year, and has no lasting symptoms from Lyme. He "came back" because we found a doctor who was trained in Lyme and was willing to treat my son with long-term antibiotics.

There are a few of those doctors in New Hampshire. But you might notice they are not here today. One of them called me yesterday and told me she planned to call the members of the Senate committee individually, rather than have her name released in public or face the scrutiny from the medical board members at this hearing. Another doctor called recently to thank me for working on this committee, and said she would definitely treat with ILADS guidelines if this legislation passed. Another told me that "because of the unknown risk to my practice, I will only treat my own long-term patients for chronic Lyme, even though I get calls every day from patients of other doctors who have not responded to short-term antibiotics. I cannot risk legal disputes. Without this legislation, she said, there is no incentive for physicians to become more educated about other guidelines; they need protection to stick their necks out."

I am not asking you today to decide which standard of care is correct. ~~That is best left to the doctors and their patients~~. New Hampshire patients need to hear all sides of the Lyme argument, and doctors need to remain open to new possibilities. That doesn't mean either party should be foolishly credulous, but they cannot be utterly dogmatic, either

~~I will remind you that we are talking about ANTIBIOTICS ... not some questionable alternative medical option. Those who consider prolonged courses of antibiotics are harmful do not seem to apply the same judgment to other infectious diseases, such as Tuberculosis or AIDS, or acne in young people.~~

I asked Tucker last night what was the most important message that he wanted me to convey to your committee today. He said, simply, "tell them I'm healthy, thanks to a doctor in Connecticut who sticks his neck out every day and wasn't afraid to treat me ... for years."

And so here I am, asking that you protect the rights of New Hampshire doctors who treat Lyme Disease based on an individualized clinical evaluation, rather than a set of guidelines that were never intended to be used for treatment, but only for reporting Lyme Disease. I ask that you give serious consideration to the testimony that you hear today. That you take the time to review the facts from both sides represented here. And that you consider "sticking your neck out" for the people you hear from today, and the thousands of others who could not be here because they are too ill. I ask that you do the right thing.

Thank you.

In 1977 legislators were asked in 17 states to step in to make sure that breast cancer patients were told about all ~~stand~~ treatment options.

Attachment 15

April 22, 2010

Madame Chairman and Members of this Committee:

Before 2004, I was considered to be in great health. I went to the doctor for an annual physical for preventive reasons only. I was an avid rock and ice climber, hiker, mountaineer, and I ran my own business successfully.

Unfortunately, my life changed dramatically in the spring of 2004. My 1st diagnoses was a spiders bite with recurring sinus infections and mono-like symptoms. My good health slowly deteriorated and my once a year doctor visits averaged 22 visits per year for two years.

My symptoms worsened as time went on with severe fatigue, heart palpitation, vertigo, Meningitis, Bell's Palsy, memory loss, slurred speech, unexplained sweats and chills, severe joint pain, poor circulation which later brought on Pulmonary Emboli, hospitalization for 2 months, MRI's, CAT scans, X-Ray's, frequent ER visits... need I say more?

I had over 5 doctors throughout NH clinically misdiagnose me. I had the Titer Test done twice with both results negative. I've been labeled with: Chronic Fatigue Syndrome, Fibromyalgia, Meniere's disease, Sjogren's syndrome, Lupus, TMJ, auto-immune deficiency, and Protein C deficiency.

My life was altered during those years with loss of employment, disability, financial hardship, loss of friendships, and depression.

In late 2005, I was clinical diagnosed and tested (using the Western Blot) and found that I have Chronic Lyme Disease along with several co-infections. I have been on long-term antibiotics for almost 5 years now. With long-term antibiotics, I can honestly say I have gotten most of my life back.

I owe my improved wellbeing to my Lyme Literate doctor. ~~who had faith in me, and has treated me on a individually needed basis.~~ I owe it to my doctor, who has more strength & COMMITMENT IN ~~toward~~ helping PATIENTS ~~others~~ achieveING their optimal health and lifestyle, than to listen to Lobbyists and the "majority rules".

Ticks, pharmaceutical companies, and insurance companies may pull the last penny I have out of my pocket, but I stand before you in support of Bill 1326 and ask each one of you to approve this bill and allow our doctors the freedom to choose the proper treatment that works for their patients.

Sincerely,

Amy Simoneau

Attachment 12

My name is Kim Schillereff.

I left a message or spoke to every NH Senator last week.

NH is #1 per the Nat'l Center For Disease Control stastistics in '08, #3 for '07 & '06.

I live in Raymond in Rockingham County, which has the highest # of reported cases in NH for '06 thru '09.
Per a UNH study from '06, at least 50% and in some locations over 70% of the ticks carry lyme disease now.

I have relatives, neigbors and friends who have lyme disease, it is amazing how many people I find/know that have it.
If you are treated immediately after discovering the tick bite, you can beat it with 30 days of antibiotics. If you don't know you have it and were misdiagnosed for years, like many of us here today, 30 days of antibiotics will not work.

I am here to fight for my doctor's right to treat my Lyme disease based upon his experience with other Lyme patients and current research. I have been on oral antibiotics since last July and was undiagnosed for many years. I was at a point where I could not lift a glass of water. I had/have many symptoms - psoriasis, heart palpations, chronic joint pain, high blood pressure that comes and goes, chest pains, anxiety attacks and difficulty with words and concentration. The strangest was the psoriasis which I had on my scalp for years and was gone within a week of taking antibiotics.

I am lucky to have a doctor who is treating me with long-term antibiotics. I warn everyone I see about Lyme disease. I want to tell everyone to see my doctor, but we both know he could lose his license. For obvious reasons, he has asked me not to release his name. I have a doctor that is treating me, but many others do not and they are the ones I am here to help.

Please pass this bill so our doctors can treat us without worrying about repercussions. They have enough to deal with just trying to help us. They know the long-term antibiotics are helping us.

I would welcome any questions.

Kim Schillereff
111 Chester Road
Raymond, NH 03077
603-895-6265

DAILY NEWS
www.newburyportnews.com

April 11, 2008

Lyme disease makes heavy push over N.H. border

By Charles Frost

Northeastern Massachusetts has long been plagued by Lyme disease-carrying ticks, but a recent study in Southern New Hampshire shows the problem is spreading rapidly over the state border.

The New Hampshire Department of Health and Human Services released data this week that indicated more than 50 percent of ticks tested last fall in Rockingham County — which includes communities such as Seabrook, Hampton and Portsmouth — were carriers of Lyme disease. That's almost twice as many as experts had initially predicted.

Since 2004, the number of confirmed cases of humans contracting Lyme disease in Rockingham County had nearly quadrupled, from 103 in 2004 to 389 last year.

While the disease can be treated with antibiotics, it also can lead to serious illness or death if not diagnosed and treated quickly.

Essex County, which includes Newburyport and surrounding towns, has had Lyme disease problems for years. According to Dr. Bela Matyas, medical director of the epidemiology program for the Massachusetts State Health Department, the county had 273 reported cases in 2006, the latest year for which

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"All over (Essex County) is considered highly endemic," Matyas said. "All over the state there are pockets of high risk and low risk; in different parts of communities there are different risks. Overall (Essex County) is a high-risk area for Lyme disease."

Matyas attributed the increase of Lyme disease in Massachusetts to ecological changes, including the return of deer to residential neighborhoods. Deer often carry the infected small, black-legged ticks.

"(Massachusetts is the) ideal habitat for Lyme disease," Matyas said. "The missing piece has tended to be deer. The deer are returning to lots of communities where they haven't been in a while."

Matyas noted that in Essex County for a very long time there has been a large number of people infected with Lyme disease, specifically 273 reported cases in 2006.

Judy Anderson, of Home Health VNA, and the public health nurse for Newburyport, West Newbury, Newbury, Georgetown and Salisbury, said that in those five communities last year there were 60 lab-reported cases of Lyme disease. But she feels that number is underrepresented because many more cases were likely diagnosed by health care providers without a lab test.

"I would say it's the most common reportable illness in those five towns," Anderson said. "That makes it in my mind a serious issue."

Matyas said people should not be worried about the increase of the number of people infected with Lyme disease, but they should be cautious.

"People should be cautious when outdoors — there are ticks," Matyas said. "Our recommendation is to try and prevent Lyme disease by preventing exposure to ticks."

Anderson said May and June are the most dangerous times to be bitten by a tick because people often don't realize that they have been bitten, because the nymph deer ticks are much smaller.

Matyas added that it takes a day to two days of a tick being attached before it can transmit Lyme disease.

Early Lyme disease symptoms can show up days to weeks after first being bitten and include a large circular rash around the bite, flu-like symptoms, fever, headache, and aching muscles and joints. People diagnosed with Lyme disease can be treated with antibiotics, but if not treated early, more serious problems can occur.

Matyas noted that Lyme disease symptoms might not show until the later stage, weeks to years after being bitten, when it affects the joints and the nervous system and is much more difficult to treat.

Matyas said the problem with Lyme diseases is that you can't know whether a tick is infected with a disease or not, without testing it.

"The truth is over the past five years the risk of disease has been spreading across more and more communities," Matyas said. "That's why our goal is to prevent exposure."

Eagle-Tribune

April 26, 2010

Conditions are right for tick population explosion

By Eric Parry
eparry@eagletribune.com

High populations of ticks and their prey have caused Rockingham County to become the perfect storm for Lyme disease.

University of New Hampshire entomologist Alan Eaton said the number of residents and suitable habitats for black-legged ticks put Rockingham County at the top of the list for Lyme disease cases in the Granite State.

"There are plenty of ticks that spread it and there are plenty of victims," Eaton said Friday.

In 2009, 567 of the 1,396 reported cases of Lyme disease were in Rockingham County, according to preliminary numbers from the state Department of Health and Human Services.

Hillsborough County is in second place with 425 reported cases.

Massachusetts also has seen an increase in the number of Lyme disease cases in recent years, according to the Massachusetts Department of Public Health. Already this year, Bay State hospitals report seeing an increase in tick bites.

Symptoms of the disease often include a large circular rash at the site of the tick

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bite, accompanied by chills, fever, headache and joint pain.

The black-legged tick, which transmits the disease to humans, is abundant within 20 miles of the Seacoast, Eaton said.

Ticks thrive in the environment found in many housing developments, a combination of wooded and clear areas, Eaton said.

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"We are creating the ideal habitat for it," he said.

Over the past 20 years, Eaton said, he's seen an increase in Lyme disease cases. This year, he isn't expecting anything different, so prepare for yet another increase in 2010.

DHHS released its annual warning Friday, cautioning people to pay attention to the black-legged tick in the next couple of months.

Ticks have been active even earlier than usual this year. As long as there is regular rainfall and no long periods of dry weather, Eaton said, there will be a risk of Lyme disease well into the fall.

"They'll be active so long as they have what they need," he said.

The worst month for Lyme disease is June because that's when the young ticks — nymphs — are most dangerous.

"That's when they peak in activity," he said.

The nymphs are more dangerous than the adult ticks because they are smaller, harder to detect and can pass the disease to the host faster.

Chris Adamski, chief of disease control with the state Division of Public Health, said there may be another reason the state is seeing an increase in Lyme disease cases.

The state has been working hard to educate people about the disease and more people may be seeing their doctor when they have potential symptoms.

"People should be really aware of it now into the fall," she said.

The best way to protect against Lyme disease is to check for ticks after being in tall grass and wooded areas where the insects live.

It's also a good idea to wear bright-colored clothing to make ticks more visible. Wearing long pants and shirts can prevent ticks from attaching to your skin.

• • •

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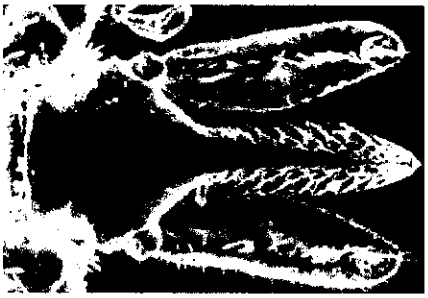
High Percentage of New Hampshire Ticks Carry Lyme Disease



50 percent to 70 percent of local ticks infected

Scientists have discovered that an unexpectedly high percentage of blacklegged ticks in New Hampshire carry the bacteria that cause Lyme disease in humans.

Research collaborators Alan Eaton, a University of New Hampshire Cooperative Extension entomologist, and Eleanor Lacombe of Maine Medical Center Research Institute, analyzed 150 adult blacklegged ticks collected in Durham , Lee and Concord , for the presence of the bacteria.

"We found more than 50 percent of the ticks from Lee and Durham and more than 70 percent from the Concord sample infected with Lyme-causing bacteria," said Eaton. "Based on evidence from previous, but limited, research in New Hampshire , we expected only about 30 percent of the ticks would carry the bacteria.

"These are preliminary data, and we need to do more work to get a complete picture of the Lyme disease risk in New Hampshire ," cautioned Eaton.

"Mid-October is the time of peak adult activity for blacklegged tick, the primary organism that causes Lyme disease in New Hampshire ," Eaton said. "People can reduce their chances of getting Lyme disease by tucking pantlegs into socks before a trip into woods or fields, using insect repellant on socks and pantlegs, and checking themselves thoroughly for ticks after a day outdoors"

"Because it takes 30 or more hours for a tick to infect you after it attaches to your body, doing a tick check every night before you go to bed so will greatly reduce your chances of getting Lyme disease," said Eaton. "An adult blacklegged tick that's just begun to feed will appear about the size of a sesame seed, but it can reach the size of a small grape as it becomes engorged with your blood."

New Hampshire is home to many other species of ticks, but the others don't spread Lyme disease," said Eaton. "In mid-October and November, the adult blacklegged tick—which used to be called the "deer tick"—is the one people are most likely to find."

"The blacklegged tick itself becomes infected with Lyme disease-causing bacteria by feeding on an infected 'reservoir host', an organism that carries high levels of the bacteria in its bloodstream," said Eaton. "In New Hampshire , the primary reservoir host for Lyme disease is the white-footed mouse."

For more information about ticks and Lyme disease:

- **NH Department of Health & Human Services' Web page on preventing Lyme disease** **(http://www.dhhs.state.nh.us/DHHS/PIO/LIBRARY/Press+Release/ocph-04tick-warning.htm)**
- **Extensive Web-based information on Lyme disease from the federal Centers for Disease Control** **(http://www.cdc.gov/ncidod/dvbid/lyme/)**
- **Biology and Control of Ticks in New Hampshire** **(http://extension.unh.edu/Pubs/HGPubs/TicksNH.pdf)**
- **Maine Medical Center Research Institute's Lyme disease research lab** **(http://zappa.mmcri.mmc.org/lyme/lymehome.html)**

Posted May 3, 2006

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Press Release List

DHHS Warns Residents of Increase in Lyme Disease

Communicable Disease Control & Surveillance

Published Date:	04/23/2010
Contact Information:	Public Information Office 603-271-6526

Concord, NH – The New Hampshire Department of Health and Human Services (DHHS), Division of Public Health Services (DPHS) is reminding people to take precautions against tick-borne diseases this season, especially Lyme disease, which has become much more prevalent in the State. DHHS has posted a prevention video on its website, www.dhhs.nh.gov, to help residents avoid tick bites and learn how to check for ticks after spending time outdoors.

"We have definitely seen an increase in cases of Lyme disease in the past few years," said Dr. José Montero, Director of Public Health at DHHS. "We had reported in 2008 that half of the black-legged (or deer) ticks sampled in Rockingham, Strafford, and Hillsborough counties tested positive for Lyme disease, and the risk is still great this year, especially with the early spring. It is not too early to take precautions as tick bites have already been reported. New Hampshire has much to offer, and we want to encourage people to enjoy the outdoors, but to do it safely."

There were 1200 cases of Lyme disease reported to DPHS in 2009, 1598 cases in 2008, and 900 in 2007. While the number of cases has shown an upward trend in recent years it is not known whether this is because of an increased number of ticks carrying the disease, a heightened awareness of the disease among patients and clinicians, or both. Early symptoms of Lyme disease often, but not always, include a large circular rash at the site of the tick bite, accompanied by chills, fever, headache, fatigue, stiff neck, swollen glands, and joint pain.

Black-legged ticks can also carry and transmit two other diseases in New Hampshire: babesiosis and anaplasmosis. These three illnesses are all preventable by avoiding being bitten by ticks. To prevent tick bites:

- Avoid tick-infested areas such as overgrown grass and brush and leaf litter
- Use insect repellent that works on ticks
- Wear long pants and sleeves when possible, and tuck pants into socks
- Do a thorough tick check after being outdoors
- Reduce ticks around your home by keeping grass short and removing leaf litter
- Monitor yourself if you are bitten by a tick and tell your healthcare provider if you develop symptoms, even if you did not notice a tick bite

For more information, visit the DHHS website at www.dhhs.nh.gov/DHHS/CDCS/default.htm, go to the Centers for Disease Control and Prevention (CDC) website at www.cdc.gov/ncidod/dvbid/lyme/index.htm, or call the DHHS Division of Communicable Disease Control and Surveillance at 603-271-4496.

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Division of Vector-Borne Infectious Diseases

Lyme Disease

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Lyme Disease Incidence Rates by State, 2004-2008*

Click on the column headers to sort by that column

State	2004	2005	2006	2007	2008
New Hampshire	17.4	20.3	46.9	68.1	92.0
Delaware	40.8	76.7	56.5	82.7	88.4
Connecticut	38.5	51.7	51.0	87.3	78.2
Massachusetts	23.9	36.3	22.2	46.3	60.9
Maine	17.1	18.7	25.6	40.2	59.2
Vermont	8.0	8.7	16.8	22.2	53.1
New Jersey	31.0	38.6	27.9	36.1	37.0
Maryland	16.0	22.1	22.2	45.8	31.0
Pennsylvania	32.1	34.6	26.1	32.1	30.7
New York	26.5	28.8	23.1	21.6	29.5
Wisconsin	20.8	26.4	26.4	32.4	26.5
Minnesota	20.1	17.9	17.7	23.8	20.0
Rhode Island	23.0	3.6	28.8	16.7	17.7
District of Columbia	2.9	1.7	10.7	19.7	12.0
Virginia	2.9	3.6	4.7	12.4	11.4
West Virginia	2.1	3.4	1.5	4.6	6.6
Iowa	1.7	3.0	3.3	4.1	2.8
North Dakota	0.0	0.5	1.1	1.9	1.2
Alaska	0.5	0.6	0.4	1.5	0.9
Illinois	0.7	1.0	0.9	1.2	0.8
Michigan	0.3	0.6	0.5	0.5	0.8
Indiana	0.5	0.5	0.4	0.9	0.7
Kansas	0.1	0.1	0.1	0.3	0.6
Montana	0.0	0.0	0.1	0.4	0.6
Oregon	0.3	0.1	0.2	0.2	0.5
Florida	0.3	0.3	0.2	0.2	0.4
Georgia	0.1	0.1	0.1	0.1	0.4
Nebraska	0.1	0.1	0.6	0.4	0.4
South Dakota	0.1	0.3	0.1	0.0	0.4
Texas	0.4	0.3	0.1	0.4	0.4
Idaho	0.4	0.1	0.5	0.6	0.3
Nevada	0.0	0.1	0.2	0.6	0.3
Ohio	0.4	0.5	0.4	0.3	0.3
South Carolina	0.5	0.4	0.5	0.7	0.3
Washington	0.2	0.2	0.1	0.2	0.3
California	0.1	0.3	0.2	0.2	0.2
New Mexico	0.1	0.2	0.2	0.3	0.2
North Carolina	1.4	0.6	0.4	0.6	0.2
Wyoming	0.8	0.6	0.2	0.6	0.2
Alabama	0.1	0.1	0.2	0.3	0.1
Kentucky	0.4	0.1	0.2	0.1	0.1
Louisiana	0.0	0.1	0.0	0.0	0.1
Missouri	0.4	0.3	0.1	0.2	0.1
Tennessee	0.3	0.1	0.2	0.5	0.1
Utah	0.0	0.1	0.2	0.3	0.1
Arizona	0.2	0.2	0.2	0.0	0.0
Arkansas	0.0	0.0	0.0	0.0	0.0
Colorado	0.0	0.0	0.0	0.0	0.0
Hawaii	0.0	0.0	0.0	0.0	0.0
Mississippi	0.0	0.0	0.1	0.0	0.0

State	2004	2005	2006	2007	2008
Oklahoma	0.1	0.0	0.0	0.0	0.0
*incidence=confirmed cases per 100,000 persons, calculated using July 1st population estimates for each year					

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Division of Vector-Borne Infectious Diseases

Lyme Disease

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Reported Lyme disease cases by state, 1999-2008

State	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008		
										Confirmed	Probable†	Incidence*
Alabama	20	6	10	11	8	6	3	11	13	6	3	0.1
Alaska	0	2	2	3	3	3	4	3	10	6	0	0.9
Arizona	3	2	3	4	4	13	10	10	2	2	6	0.0
Arkansas	7	7	4	3	0	0	0	0	1	0	0	0.0
California	139	96	95	97	86	48	95	85	75	74	0	0.2
Colorado	3	0	0	1	0	0	0	0	0	2	1	0.0
Connecticut	3215	3773	3597	4631	1403	1348	1810	1788	3058	2738	1158	78.2
Delaware	167	167	152	194	212	339	646	482	715	772	0	88.4
DC	6	11	17	25	14	16	10	62	116	71	3	12.0
Florida	59	54	43	79	43	46	47	34	30	72	16	0.4
Georgia	0	0	0	2	10	12	6	8	11	35	0	0.4
Hawaii	0	0	0	0	0	0	0	0	0	0	0	0.0
Idaho	3	4	5	4	3	6	2	7	9	5	4	0.3
Illinois	17	35	32	47	71	87	127	110	149	108	0	0.8
Indiana	21	23	26	21	25	32	33	26	55	42	0	0.7
Iowa	24	34	36	42	58	49	89	97	123	85	24	2.8
Kansas	16	17	2	7	4	3	3	4	8	16	0	0.6
Kentucky	19	13	23	25	17	15	5	7	6	5	0	0.1
Louisiana	9	8	8	5	7	2	3	1	2	3	0	0.1
Maine	41	71	108	219	175	225	247	338	529	780	128	59.2
Maryland	899	688	608	738	691	891	1235	1248	2576	1746	472	31.0
Massachusetts	787	1158	1164	1807	1532	1532	2336	1432	2988	3960	622	60.9
Michigan	11	23	21	26	12	27	62	55	51	76	16	0.8
Minnesota	283	465	461	867	474	1023	917	914	1238	1046	236	20.0
Mississippi	4	3	8	12	21	0	0	3	1	1	0	0.0
Missouri	72	47	37	41	70	25	15	5	10	6	0	0.1
Montana	0	0	0	0	0	0	0	1	4	6	11	0.6
Nebraska	11	5	4	6	2	2	2	11	7	8	4	0.4
Nevada	2	4	4	2	3	1	3	4	15	9	3	0.3
New Hampshire	27	84	129	261	190	226	265	617	896	1211	390	92.0
New Jersey	1719	2459	2020	2349	2887	2698	3363	2432	3134	3214	271	37.0
New Mexico	1	0	1	1	1	1	3	3	5	4	4	0.2
New York	4402	4329	4083	5535	5399	5100	5565	4460	4165	5741	2053	29.5
North Carolina	74	47	41	137	156	122	49	31	53	16	31	0.2
North Dakota	1	2	0	1	0	0	3	7	12	8	2	1.2
Ohio	47	61	44	82	66	50	58	43	33	40	5	0.3
Oklahoma	8	1	0	0	0	3	0	0	1	1	1	0.0
Oregon	15	13	15	12	16	11	3	7	6	18	20	0.5
Pennsylvania	2781	2343	2806	3989	5730	3985	4287	3242	3994	3818	0	30.7
Rhode Island	546	675	510	852	736	249	39	308	177	186	24	17.7
South Carolina	6	25	6	26	18	22	15	20	31	14	15	0.3
South Dakota	0	0	0	2	1	1	2	1	0	3	0	0.4
Tennessee	59	28	31	28	20	20	8	15	31	7	24	0.1
Texas	72	77	75	139	85	98	69	29	87	105	48	0.4
Utah	2	3	1	5	2	1	2	5	7	3	2	0.1
Vermont	26	40	18	37	43	50	54	105	138	330	74	53.1
Virginia	122	149	156	259	195	216	274	357	959	886	47	11.4
Washington	14	9	9	11	7	14	13	8	12	22	1	0.3
West Virginia	20	35	16	26	31	38	61	28	84	120	15	6.6
Wisconsin	490	631	597	1090	740	1144	1459	1466	1814	1493	541	26.5
Wyoming	3	3	1	2	2	4	3	1	3	1	2	0.2
U.S. TOTAL	**16,273**	**17,730**	**17,029**	**23,763**	**21,273**	**19,804**	**23,305**	**19,931**	**27,444**	**28,921**	**6,277**	**9.4**

† 2008 revision of the National Surveillance Case Definition allows for reporting of probable cases

* confirmed cases per 100,000 population

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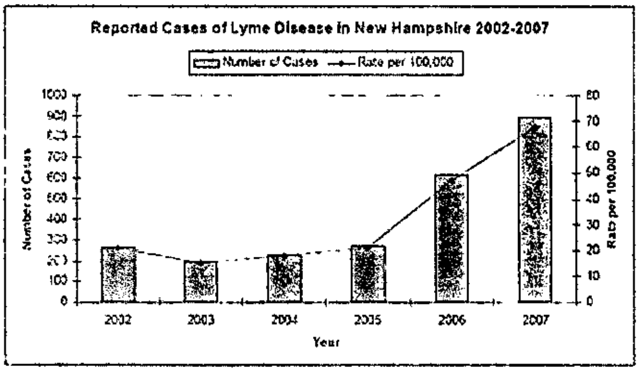
disease in New Hampshire including incidence, geographic distribution per county, and other related data.

New Hampshire Incidence

The number of New Hampshire residents diagnosed with Lyme disease and reported to the NH Department of Health and Human Services (DHHS) has increased in recent years. The highest rates of disease occurred in Rockingham, Strafford, Hillsborough, Merrimack, and Carroll Counties.

Tick numbers

- Black-legged ticks are common in southeastern New Hampshire (Strafford, Rockingham, Hillsborough, Merrimack Counties); large numbers of ticks were collected in these locations.
- Black-legged ticks are rare in northern and mid-western New Hampshire (Sullivan, Coos, Grafton Counties); no ticks were able to be collected in these locations.
- Black-legged ticks are less common in southwestern and mid-central New Hampshire (Cheshire, Belknap, Carroll Counties); few ticks were able to be collected in these locations.



County		2006	2007
Belknap	Number of Cases	10	6
	Rate per 100,000	16	10
Carroll	Number of Cases	5	19
	Rate per 100,000	11	40
Cheshire	Number of Cases	12	13
	Rate per 100,000	15	17
Coos	Number of Cases	4	3
	Rate per 100,000	12	9
Grafton	Number of Cases	7	14
	Rate per 100,000	8	16
Hillsborough	Number of Cases	150	216
	Rate per 100,000	37	54
Merrimack	Number of Cases	29	47
	Rate per 100,000	20	32
Rockingham	Number of Cases	312	389
	Rate per 100,000	106	131
Strafford	Number of Cases	88	182
	Rate per 100,000	73	150
Sullivan	Number of Cases	2	3
	Rate per 100,000	5	7
Total	Number of Cases	619	892
	Rate per 100,000	47	68

Attachment 17

Hello My name is Erin Fallon and I live in Strafford NH. I am married to Tony Fallon whom you have heard from previously today. We have 3 children ages 27, 24 and 20. All 3 of our children where born with lyme disease. All three of our children contracted the disease from me. I contracted Lyme disease growing up in rural Ct where I had multiple tick bites with bull-eye rashes, and developed a litany of symptoms that continued undiagnosed for many years.

Since Lyme is a relapsing remitting sort of disease, and the testing is based on having a healthy immune response to a two tiered series of IDSA tests that are remarkably inacurate, my children and I went many years with health ups and downs before each of us was able to get a diagnosis.

For me it was almost 6 yrs ago, I was in graduate school and working part time in a physical therapy practice. I suddenly had drastic memory loss and seizures. I was referred to a ILADS Dr from CT as my only option for care. HE put me emediately on IV abx. I began to recover. We treated ~~to~~ for infection, and I recovered more, then I got worse. The years of not treating had allowed my body to develop a rare generative neurologic disease. Now I'm on weekly treatment for that as well as continued abx. The fun never ends.

My eldest daughter had a sinus infection & body aches that wouldn't clear. She was living out of state. I told her to see and Ilads dr. She tested + for lyme and did many months of oral abx and is diong fine.

My younger daughter got reinfected with a new strain of lyme while runnine cross-country in high school. She went off to run in college and developed hip pain and head aches and problems concentrating. I took her to my Ilads dr in CT She tested + for ~~my~~ lyme and all co-infections and was treated for 2 yrs with oral abx. she is doing well.

MY son is 20 and still struggling. He lost his ablitly to read when he was 15 as the infection hit his brain at puburty. HE needed to be taught to think oragainze and remember again. Private testing showed significant cognitive loss. He lost friends because he couldn't remember conversation or humor. he was labled lazy and stupid by teachers at the local school. He could not get an IEP because Dr. [illegible] at the school said that chronic lyme does not exist. We pulled him from public school and borrowed against out home to send him to a private prep school where he would get tutoring and coaching. He did well.
HE went off th Phylmouth state university, and his lyme disease relapsed. HE is now back on abx and other meds to help him keep his brain focused. he works to get extra tutoring. He has no memory of his childhood, but he's ~~owkring~~ working hard to not lose memory of his present.

Attachment 18

State of New Hampshire – Senate Hearing on HB 1326 April 26, 2010

Testimony of Arlene Stoppe
85 Leavitt Hill Road, Ashland, NH 03217
Home: (603) 968-4478, Cell: (603) 481-0374

In June of 2009 I woke up and tried to stand. I felt like a crippled little old lady, at the ripe age of 48. I couldn't straighten or bend my fingers which were curled up on both hands. I couldn't stand up straight. It felt like I was walking on skin & bones. My joints hurt all over. I was profoundly tired. After limping around a bit and flexing my fingers for a while, I was able to straighten up, but the joint pai~~d~~n was still there.

Every day for many months I woke up curled and crippled.

I won't bore you with all the problems and symptoms I have had over the last 20 years, seeing many different doctors at different hospitals, only to have no diagnosis or treatment.

In early September 2009 I was diagnosed with Chronic Lyme Disease. I have been on long term treatment with antibiotics ever since. This is what I need to get better.

Today, I have less joint pain and I do not wake up with my body all crooked each day. I still have symptoms but I am improving. I assure you my inprovement is not from placebo!

I am living proof that Chronic Lyme Disease does exist and it can be successfully treated with long term antibiotics.

I spoke with a doctor friend of mine a couple of days ago. I will refer to him or her as Dr Jane Doe. This doctor told me she believes Chronic Lyme patients need the long term antibiotics. When she prescribed more than a few weeks of an antibiotic to a Lyme patient, she was questioned by her supervisor & told that is not the standard. She is afraid of prescribing what she knows will help the patient. Dr. Doe now refers Lyme patients to other doctors.

We need our doctors to be able to treat us, NOW! Not Next year & not 5 or 10 years from now.

I am in favor of HB 1326. Please pass this legislation today. Time is of the essence since Lyme disease can be FATAL if not treated.

Attachment 19

Whitney Williams <whitney.williams@gmail.com>

lyme testimony

Whitney Williams <whitney.williams@gmail.com> **Sun, Apr 25, 2010 at 11:40 PM**
To: Whitney Williams <whitney.williams@gmail.com>

My name is Whitney Williams
I am from Manchester, New Hampshire.
Over the years doctors have diagnosed me with: Depression, Anxiety, ADD, Bipolar Disorder, Insomnia, TMJ, Meneire's Disease, Fibromyalgia, Chronic Fatigue Syndrome, and more.
I believe I have had Lyme Disease for 14 years. I am also being treated for Bartonella.

It is hard to write this. It is hard because my body aches and I am exhausted and my neurological symptoms of chronic Lyme Disease make words I have known my entire life an empty space in my mind. A hole where a word used to be. It is hard because even simple things are hard. Some days are very dark. Some days are very lonely. Some days are desperate and angry and hopeless. Some days, I feel it all.

I am angry to be 27 and missing out on my life. On days like today I cannot spell my first name and I cannot hold a pen because my fingers hurt so badly and I cannot perform simple tasks related to my job. On days like today I cannot keep track of what I am doing as I am doing it. On days like today, accomplishing anything meaningful is a rare accident. On days like today the anger doesn't run out. Everyday has become a day like today.

I feel that a crime has been committed against my life, my body. I feel my happiness, my health, all my potential as a human being has been held hostage with no ransom. I am a victim of mediocre practice of medicine, a casualty of a for-profit machine engineered to treat patients as casually as consumers at Walmart buying a microwave, not as people. And I am one in millions.

I have arrived at doctor office after office, a typed list in hand, and a sense of desperate hope despite the inevitable and persistent disappointments and dismissals. That hope was constructed of what I knew at a cellular level, something was wrong with me and I was wasting my life submitting to a nameless captor. I knew this with every step I have taken on this earth, with every pill I had uselessly popped, with every night I wept myself to sleep, with every breath. I knew, I didn't just believe something was wrong with me, I knew. What I don't know is how my heart still manages to break so sharply, why it aches so freshly with this repeated and deafening loss. What I don't know is if the grief for what I have lost will ever run out.

Despite my questions, despite my multitude of symptoms and vast history, no doctor until recently cared to consider what might cause such a poor quality of life. No one thought it was strange for someone so young to be so unhealthy, to be so thoroughly damaged in so many ways, that they either thought I was lying or I didn't know that I was making it up. I pointed out the strangeness of my list, I acknowledged that I was a challenge. Eventually, my hope was beaten out of me. I stopped looking for answers. I stopped believing I would ever feel different.
I am humbled by this disease. These magnificent, malicious, and miraculously small but brilliant bugs are beating the shit out of me. There is no poetry here. There are no moments of grace. There are no words adequate. There is no heart big enough.

My current Doctor is the first person to believe I should and could feel different. My current Doctor is the first medical professional to make a real investment in me, to practice the kind of medicine all other doctors in my life seem to have forgotten. My current doctor is the first doctor who didn't recoil from the words "Lyme Disease", and who didn't bat an eyelash when I expressed my fears about what my Health Insurance might do if we tried to treat me with antibiotics for as long as it takes. My current doctor has a heart big enough to help heal me.

There is nothing more I want from this life than to be free of these bugs. Nothing. All I ask from you today is that you help protect the choices I make about my health with the guidance of my physician. The supposed risks of long term antibiotic usage are my own, and the reality is, there is no risk I would not take to avoid living the rest of my life crippled and unable to spell my own name.

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^^^^^^^^^^^^^^^^^^^^^^^^^^^^^^^^

Whitney Williams
603-731-2957
whitney.williams@gmail.com
wwilliams@nhia.edu
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"Every choice we make can be a celebration of the world we want." -Frances Moore Lappé

Attachment 20

April 26, 2010

To the Senate Executive Departments and Administration Committee:

Our country was founded on an idea. An idea from the Enlightenment that all human beings are innately intelligent, capable of reason and are therefore qualified to self-govern. The Enlightenment philosophers also recognized the moral conflicts which make this so difficult. I believe it is important to remember this simple founding principle as a guidepost to one of the most difficult and challenging conditions of governance that we the people, and you, the government face: the health,well-being and subsequent "right to life"of all people. The founders guaranteed us the right to make choices concerning our own health and well-being. They could not, however, have imagined the current nexus of the medical/industrial/governmental complex that has fouled this simple, moral premise. Nowhere is this more pungent than within the Lyme paradigm.

I would like you to listen to these words-

"After listening to the commencement speech by Steve Jobs, I realized that the single most devastating thing about fighting chronic lyme disease is not the endless, consuming pain, or the unfathomable fatigue, or the loss of my mental faculties. No. It is the deafening roar all this creates that drowns out my dreams. ... The noise of this disease takes up so much space that there is no room for my heart to speak. That is the hardest part".

This was written in a personal e-mail to me on Saturday ...by my daughter. Clearly, you as a body have a choice here and with it comes a high degree of moral liability. Immanuel Kant would caution you to make this decision in the light of the greater good, respecting the innate capacity of all human beings to make their own choices. Within the framework of our governance I urge you support HB 1326 and do the right thing . Thank- you

Viki Williams
445 Francestown Rd
Greenfield, NH 04047

Attachment 21

testimony Monday, April 26, 2010 10:26:47 AM

From: laupiazza@comcast.net
To: laupiazza@comcast.net

In the summer of 2008 my sister Gina, a Doctor of Osteopathic Medicine, was in touch with me in fear that she had finally figured out why she was so sick. In the research about her own symptoms she discovered the controversy surrounding Lyme Disease and this opened her eyes to what could be wrong. She'd gone misdiagnosed for over 20 years. Her discovery of chronic lyme made her realize that I exhibited the signs and symptoms of it as well. She was right.

I've been in treatment for 15 months now. My PCP who I had seen for years and gotten along with so well was "not comfortable" working with my Lyme specialist. So I had to find a new Doctor and this was no easy task.

For my Lyme disease treatment I drive five hours each way to see my Lyme specialist. I am thankful that my medical insurance has paid for most of my medication. Unfortunately though, my Lyme doctor is considered out-of-network, as are some of the labs, and medications so these expenses are not covered. Given this and the amount of supplements and probiotics which are part of treatment, I've already spent nearly $15,000 out of pocket. The time commitment and financial burden I have felt from this illness is truly staggering. I feel such gratitude to my Lyme doctor for his quest for knowledge, skills in treating, and willingness to prescribe long-term antibiotics. Without this I am can't begin to imagine what my life would be like now.

1 I know of many people plagued with this illness who have had their insurance company deny payment or even drop them. Why? They say chronic lyme does not exist. Life insurance companies, however, believe the contrary. I know this because I, a 34 year-old otherwise healthy women, was denied for life insurance on account of my chronic Lyme Disease. This double standard is very telling.

2 We have so few Lyme literate doctors in the state. The PCP I did find is in full support of my treatment and she is involved in my care. She told me when i started there to please not to tell people that she treats Lyme. Just last week she told me that she had a patient who she put on 28 days of IV therapy for their Lyme. They had made great strides and were 60% better so she wanted to prescribe another month. The pharmacist said this was out of the IDSA guidelines, refused and reported her to her employer. She's dedicated to her patients and will likely continue to do what she thinks is best for them. Many doctors may be scared off by this. This is the type of thing that house bill 1326 would prevent.

In a state that is endemic we need our doctors to be educated about not only treating long term Lyme but also know how to recognize and treat the early onset so that it's treated in the window when it can be eradicated and won't becomes chronic..

Any doctor treating Lyme is doing so knowing full well that they put themselves at risk. These doctors should be protected and commended as they are the true heroes.

I ask you to please think of me and all of the others who are suffering and **vote in favor of HB1326.**

Laura Piazza Herd
PO Box 881
Sunapee, NH 03782

603-763-9561

Attachment 22

My name is Bob Perry, representing house district No. 3, the towns of New Durham, Milton, Middleton, Farmington, Barrington, and Strafford, and I speak on their behalf in support of HB. 1326.

The intent of H.B. 1326 is simple: Passage would allow doctors to know they can practice their profession without fear of disciplinary action, in a manner that suits the long-term needs of their patients infected with chronic Lyme disease, and assuring the patient that he or she is being advised of, and has access to, peer-reviewed, evidence-based, treatment options. Nothing more. Nothing less. Indeed, the American Medical Association ***requires*** that physicians disclose and discuss with their patients the risks and benefits of the proposed treatment, as well as the risks and benefits of ***all available*** treatments.

You will hear it said today that there are two federally recognized bodies of medical science whose conclusions differ as to the existence of chronic Lyme disease. Because of the political and economic climate surrounding the long-term treatment of Lyme disease in New Hampshire, many with the disease must seek relief from doctors outside this state. We are not asking you to support a bill that legislates one approach to Lyme disease over another, or to legislate a new standard of care, or to legislate an exception to medically based care and treatment. Not at all. Simply, we are asking you to allow New Hampshire doctors evidence-based options of treating chronic Lyme disease, subject to individualized clinical evaluation, consistent with one of the two federally recognized approaches to long-term care.

Why Lyme disease? Why New Hampshire? Why now?

Lyme disease is the fastest-growing infectious disease in the United States. According to the Centers for Disease Control (CDC), New Hampshire now has the highest incidence of Lyme disease, per capita, among the 50 states. The highest.

Unfortunately, diagnosis and treatment of Lyme disease is frustrated by the limited sensitivity of current testing methods in the human body, resulting in many false negatives, which means many victims of bites from infected ticks will carry the bacteria that causes Lyme disease after they have been tested and told by their doctors they are free of the bacteria. Approximately 50 percent of persons identified as having Lyme disease never remember being bitten by the tick that introduces the bacteria. Tests indicate that up to 77 percent of deer ticks in New Hampshire are infected with the bacteria that causes Lyme disease.

Between early April and August 1, last year, I removed 30 ticks from my skin and clothing. One even dropped out of my scivvies. The only ticks I could actually feel roaming my skin were the ones at the base of my neck, which I captured under my fingernail. Of the 30, approximately four had begun to attach, so that when I removed those ticks, a patch of skin was also removed.

On February 10 of this year, the middle of winter, a friend removed a tick which had imbedded in his chest as he slept. On April 9 of this year, I, too, removed a tick from my scalp, along with a piece of skin, immediately upon awakening. A few days later, I removed another tick headed for my armpit. Since April 9, I've removed two ticks from my dog's ear, and just yesterday (Sunday) removed a blood-filled tick from her shoulder.

We are *all* vulnerable to ticks and their bites, whether inside or outside the home, whether country or city dwellers. When we become the unwitting recipient of their bite and infection, we must know that the ***full measure*** of medical options for our recovery is available to us. H.B. 1326 is not about ticks. It's not about mandates. It's about compassion for those currently suffering with the disease, and for those who will become victims of chronic Lyme disease into the foreseeable future. It's about allowing doctors to practice their professions in a manner consistent with a history of successful outcomes. It's about the sanctity of the doctor/patient relationship. Thank you.

Infectious Disease Society of America [IDSA]

The International Lyme and Associated Diseases Society (ILADS)

Attachment 23

HB-1326 Senate Testimony, April 26, 2010
Rep. John Cebrowski, representing Hillsborough 18, the town of Bedford

Thank you Madame Chair…

I supported this bill, jumped into this fight, and spoke on the floor of the House in favor of it, for four reasons:

1. I spent most of my business career in the medical technology / hospital environment and am very accustomed to hearing differing treatment opinions. Medical debates go on all the time. How many times have you heard, on behalf of yourself or a family member, that it is a good idea to seek a second medical opinion? How would you feel if the ability to get second opinions, second opinions based on evidence-based medicine, and *act* on those second opinions, were snuffed out for you and your family?

2. Several long-time friends—highly respected members of my community—came forward to share their experience. Their integrity and credibility is unassailable. The challenging climate surrounding the treatment guidelines translated into long-term health problems and diminished access to care for them—because of the perception and/or actions that medical boards will act against some physicians who do not adhere to IDSA guidelines. This has had a chilling effect on the number of doctors who specialize in Lyme and who are trained and willing to treat this complex disease. The net result? It was real tough to get real help!

3. I did a little research and spoke to Connecticut Asst. Attorney General Thomas Ryan. He told me that their office had received a complaint from a group of citizens some time ago based on this conflict. After study, the AG's office felt an anti-trust approach was best and an investigation of the Infectious Disease Society of America, and its Lyme Disease guideline panel, was launched. Attorney Gen. Richard Blumenthal found that his antitrust

investigation uncovered serious flaws. Blumenthal said, *"The IDSA's Lyme disease guideline panel undercut its credibility allowing individuals with financial interests—in drug companies, Lyme disease diagnostic tests, patents and consulting arrangements with insurance companies—to exclude divergent medical evidence and opinion."* Mr. Ryan added, *"The IDSA process was manipulated. We can't prosecute freedom to treat, doctors have the freedom to treat as they see fit."*

4. Last year the Connecticut House passed a similar bill…a bill initiated by a couple of State Representatives whose family members had chronic Lyme and experienced first-hand the difficulty in getting proper care. There were 112 co-sponsors! It came out of committee 30-0! The House vote was 137-0! The Senate was also unanimous. I spoke to Connecticut House Democratic Leader Denise Merrill: In response to my question: *"How in the world did this happen"*? She said, *"We're allowing doctors to decide. We shouldn't be deciding. We shouldn't be making medical decisions. We're simply allowing it, leaving it to the doctors."* In response to the same question, Larry Cafero, Connecticut House Republican Leader, agreed, and offered a similar response to Denise.

I thank you all for your endorsement and positive vote on this important bill!

Thank you Madame Chair…

Speakers

①

IN FAVOR

Senate Executive Departments and Administration Committee: Sign-In Sheet

Date: April 26, 2010 Time: 1:00 p.m. Public Hearing on HB 1326

HB 1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

Name PLEASE PRINT	Representing				
1. Rep. Gary Daniels	sponsor	Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
6. David Hunter		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
8. Greg Kettmann		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
4. Dr. Samuel Donta		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
2. Dr. Kevin Young		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
Exec. Coun. Ray Burton		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
41 Rep. Robert Perry		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
42 Rep. John Cebrowski		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
43 Rep. Claudia Chase		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
10. June Cormier	Left	Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
12. Jacqueline Arlen		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
13. Marie Veselsky		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
14. Carl Tuttle		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
15. Jessica Wojenski		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
16. Peter Ballou		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
17. Tony Fallon		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
18. Julie Hall		Support ☒	Oppose ☐	Speaking? Yes ☒	No ☐
~~Susan Patterson~~		~~Support ☒~~	Oppose ☐	~~Speaking? Yes ☒~~	~~No ☐~~
		Support ☐	Oppose ☐	Speaking? Yes ☐	No ☐

IN FAVOR

Senate Executive Departments and Administration Committee: Sign-In Sheet

Date: April 26, 2010 Time: 1:00 p.m. Public Hearing on HB 1326

HB 1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

Name PLEASE PRINT **Representing**

✓ Rep Suzanne Smith	Grafton 7	Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☒
✓ Rep Phil Preston	Grafton 8	Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
✓ Diane J. NORMAND	Self	Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☒
✓ Krista Passon	self	Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
✓ Jean Amsden	self/family members	Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
✓ JAMES R KALLOCH	SELF	Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
✓ Lynn R. Aramini	self	Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
19. Barbara A. Flower	family member	Support ☑	Oppose ☐	Speaking?	Yes ☑	No ☐
20. James L. Flower	family	Support ☑	Oppose ☐	Speaking?	Yes ☑	No ☐
✓ Deborah Hemeon	Self	Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☒
21 Marilyn Rivera	self	Support ☑	Oppose ☐	Speaking?	Yes ☑	No ☐
✓ Martha Madsen	my daughter	Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
✓ GLENNA DANIELS	FRIEND	Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
22 Laura C. Gray	Self	Support ☒	Oppose ☐	Speaking?	Yes ☒	No ☐
✓ PAUL LINDEMANN	Self	Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☒
23. Amy Simoneau	Self	Support ☒	Oppose ☐	Speaking?	Yes ☒	No ☐
✓ Lair Tourangian	grand daughter	Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☒
✓ Helen Ballon	self	Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐

IN FAVOR

Senate Executive Departments and Administration Committee: Sign-In Sheet

Date: April 26, 2010 Time: 1:00 p.m. Public Hearing on HB 1326

HB 1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

Name PLEASE PRINT	Representing	Support	Oppose	Speaking?	Yes	No
Jake Wojenski	self	☑	☐	Speaking?	☐	☑
Lisa Wojenski	Self	☑	☐	Speaking?	☐	☑
Holly Franz	self	☑	☐	Speaking?	☐	☑
Tyler Monson	self	☑	☐	Speaking?	☐	☑
Dana Bourassa	SELF	☑	☐	Speaking?	☐	☑
Michelle O'Mara	self	☑	☐	Speaking?	☐	☑
24 Kim Schillereff	self	☑	☐	Speaking?	☑	☐
Hank Amselon	"	☑	☐	Speaking?	☐	☑
Elaina Powell	self	☑	☐	Speaking?	☐	☑
Elizabeth Fales	self	☑	☐	Speaking?	☐	☑
(25.) Stephanie Davis	self Had to leave	☑	☐	Speaking?	☒	☒
Mary Mazur	self	☒	☐	Speaking?	☐	☑
Frank Mazur	self	☒	☐	Speaking?	☐	☑
Warren Hyde	self	☑	☐	Speaking?	☐	☑
Ann Robinson	Self	☑	☐	Speaking?	☐	☑
[illegible]	Daughters	☑	☐	Speaking?	☐	☑
26 Holli M'Ginn	self	☑	☐	Speaking?	☑	☐
Rep Carol Vita	STRAFFORD 3	☒	☐	Speaking?	☐	☒
22. Erin Fallon	self	☒	☐	Speaking?	☒	☐

④

IN FAVOR

Senate Executive Departments and Administration Committee: Sign-In Sheet

Date: April 26, 2010 Time: 1:00 p.m. Public Hearing on HB 1326

HB 1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

	Name PLEASE PRINT	Representing					
28	Arlene Stoppe	self	Support ☑	Oppose ☐	Speaking?	Yes ☑	No ☐
✓	Debra Kontrovitz	sister	Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☒
✓	Chelli Tennis	Self	Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
✓	Mary Fanslau	Self	Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☑
✓	Ellen Young	Self	Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
~~29~~	~~Greg Kettmann~~	~~Self~~	~~Support ☒~~	~~Oppose ☐~~	~~Speaking?~~	~~Yes ☒~~	No ☐
✓	Cathy Kettmann	Self	Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☒
30	Whitney Williams	Self	Support ☒	Oppose ☐	Speaking?	Yes ☒	No ☐
31	Viki Williams	Self	Support ☒	Oppose ☐	Speaking?	Yes ☒	No ☐
32	Susan Patteson	Self	Support ☒	Oppose ☐	Speaking?	Yes ☒	No ☐
33	Laura Piazza Herd	Self	Support ☒	Oppose ☐	Speaking?	Yes ☒	No ☐
34	Douglas Newton	Self	Support ☒	Oppose ☐	Speaking?	Yes ☒	No ☐
35	~~Laura Schwartz~~	self	~~Support ☒~~	~~Oppose ☐~~	Speaking?	~~Yes ☒~~	~~No~~ ☐
36	~~Claudia Chace~~		~~Support ☒~~	~~Oppose ☐~~	~~Speaking?~~	~~Yes ☒~~	~~No ☐~~
37	CHERYLANN VICTOR	SELF	Support ☒	Oppose ☐	Speaking?	Yes ☑	No ☐
44	Rep. Peter Schmidt	Straf. 4	Support ☒	Oppose ☐	Speaking?	Yes ☒	No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐

5

IN FAVOR

Senate Executive Departments and Administration Committee: Sign-In Sheet

Date: April 26, 2010 Time: 1:00 p.m. Public Hearing on HB 1326

HB 1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

Name PLEASE PRINT	Representing					
Rep. Timothy Horrigan	Grafton #2	Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☒
Igner Reelaster		Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☒
Pam Veiga	Self	Support ☑	Oppose ☐	Speaking?	Yes ☑	No ☐
Tanya Renner	Self	Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☐
Lewis Rosenthall		Support ☐	Oppose ☐	Speaking?	Yes ☑	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐

⑥

IN FAVOR

Senate Executive Departments and Administration Committee: Sign-In Sheet

Date: April 26, 2010 Time: 1:00 p.m. Public Hearing on HB 1326

HB 1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

Name PLEASE PRINT	Representing					
✓ Larisa Molloy		Support ☒	Oppose ☐	Speaking?	Yes ☐	No ☒
38 ~~Tony Fallon~~	~~Self~~	~~Support ☑~~	~~Oppose ☐~~	~~Speaking?~~	~~Yes ☑~~	~~No ☐~~
39 ~~Kary Jencks~~	Self	~~Support~~ ☒	~~Oppose~~ ☐	Speaking?	Yes ☑	No ☐
✓ Susan Tufts-Moore		Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
✓ Matthew T. Moore		Support ☑	Oppose ☐	Speaking?	Yes ☐	No ☑
40 PAMELA BROWN	SELF	Support ☑	Oppose ☐	Speaking?	Yes ☑	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐
		Support ☐	Oppose ☐	Speaking?	Yes ☐	No ☐

①

OPPOSED

Senate Executive Departments and Administration Committee: Sign-In Sheet

Date: April 26, 2010 Time: 1:00 p.m. Public Hearing on HB 1326

HB 1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

	Name PLEASE PRINT	Representing				
B. ✓	John Robinson, MD	NH Medical Society	Support ☐	Oppose ☒	Speaking?	Yes ☒ No ☐
S. ✓	Robert Andelman, MD	NH Bd of Medicine	Support ☐	Oppose ☒	Speaking?	Yes ☒ No ☐
T. ✓	Jeffrey Parsonnet, MD	Dartmouth-Hitchcock	Support ☐	Oppose ☒	Speaking?	Yes ☒ No ☐
G. ✓	Gail Abarba	BOM.	Support ☐	Oppose ☑	Speaking?	Yes ☒ No ☐
H. ✓	Jose' Montero	DHHS-DPHS	Support ☐	Oppose ☒	Speaking?	Yes ☒ No ☐
H.	Beth Sargent	NH Pharmacists Assoc.	Support ☐	Oppose ☒	Speaking?	Yes ☐ No ☒
✓	PAULA ROGERS	Anthem Health Plans	Support ☐	Oppose ☒	Speaking?	Yes ☐ No ☒
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐
			Support ☐	Oppose ☐	Speaking?	Yes ☐ No ☐

2

OPPOSED

Senate Executive Departments and Administration Committee: Sign-In Sheet

Date: April 26, 2010 Time: 1:00 p.m. Public Hearing on HB 1326

HB 1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

Name PLEASE PRINT	Representing		
Louis E. ROSENTHAL//MD	NH BOM	Support ☐ Oppose ☒	Speaking? Yes ☐ No ☒
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐
		Support ☐ Oppose ☐	Speaking? Yes ☐ No ☐

Testimony

Submission A

My name is Laura Schwartz. I live in Stratham, NH.

My lyme symptoms started in the summer of 2007. At that time, I was in great physical shape, working out almost every day and competing in triathlons. I had extreme pain in my calves, nervousness, shakiness, chills, forgetfulness, inability to concentrate and general malaise that left me bedridden on several days. I could not stand up for more than 20 minutes at a time. Most days, I would get home from work and go to bed. I could not even take my boys trick or treating that year.

I saw 12 specialists over the course of the following year. None of them could find anything wrong with me. All of my many tests (which included 2 Elisa lyme tests) were negative. I had an MRI, full neurological and rheumatology work up, ultrasound, and x-rays. I was deemed a healthy then 44-year old. I knew otherwise.

Finally, I got a diagnosis – lyme disease. Luckily, my GP gave me some good advice – seek out a lyme literate doctor and chances are, I will have to go out of NH to find one. Several days of research on the web led me to a LLMD in Massachusetts. After reviewing my blood work and doing an extensive clinical evaluation, he started me on an open-ended course of antibiotics. Because I had been sick for a year, it was going to take time for the antibiotics to kill off the spirochetes that had made a home throughout my body.

After 6 months on antibiotics, I felt 80% better. It was such a joy to be getting back into life after a year of struggling to just make it through the day. I am still on antibiotics today – it has been 20 months. I know I need long term antibiotics. The recommended course by the IDSA Guideline is 4-6 weeks. At 4-6 weeks, I was still very sick. I tried going off the antibiotics at 17 months and the symptoms returned. I resumed the antibiotics and my recovery continues.

I am extremely grateful to my LLMD for his expertise and courage. I am confident that I will make a full recovery. I strongly support House Bill 1326. This bill does not legislate care, but gives the doctors the freedom to make treatment decisions on a case by case basis.

Submission B

Chroniak, Deborah

From: Pamela A.Veiga [paveiga@charter.net]
Sent: Monday, April 26, 2010 8:53 AM
To: Cilley, Jacalyn; Fuller Clark, Martha; DeVries, Betsi; Downing, Michael; Carson, Sharon
Cc: Gargasz, Carolyn; Ryder, Donald; Gilmour, Peggy
Subject: HB1326. Please enter into testimony for HB 1326

Good morning Senator Carson and distinguished colleagues of the Senate ED & A Committee.

You have before you HB 1326 at 1:00 pm today.

I would like to strongly encourage you to vote FOR helping doctors treat Lyme with long term antibiotics in NH.

This disease is prolific especially in the southern tier of the state. I have a Lyme disease husband who is the poster child for Lyme disease recovery thanks to an 9 month regime of antibiotics. The irony of all this is that we are very ANTI antibiotic treatment for anything for the past 20 years and solve many issues of health with herbs, homeopathy, nutrients and the like. It is truly ironic we would want this for anyone. My husband Tory owns his own company and is a working electrician who is Adonis like in body shape and the picture of health...until Lyme. At the pinnacle of his joint pain due to the Lyme disease, he crawled up the stairs on hands and knees and we knew it was time to do something. Over the next 6 months after a Herx reaction, he was bicycling 28 miles one day and running 6 miles the alternate day. He was astounded by the results. This antibiotic regime included probiotics throughout to support re-population of good bacteria inthe gut.

Between my own students at Nashua Community College, massage clients who include MD's, neighbors and colleagues, I am surrounded with people with Lyme.

Please support the passage of this bill and allow these people to get help!

Thank you!!!!
Pam Veiga
43 Black Oak Drive
Hollis, NH 03049

Pamela Veiga
A. Professor, Program Coordinator
~Massage Therapy Certificate Program
~Complementary Health and Wellness Certificate Program
Nashua Community College
505 Amherst Street
Nashua, NH 03063
(603) 882-6923 ext.1442
pveiga@ccsnh.edu
www.nashuacc.edu

"Massage Therapy has been shown to effect many functions and medical conditions in different age groups. Among the significant research findings are enhanced growth (e.g. in preterm infants), diminished pain (e.g. fibromyalgia), decreased autoimmune problems (e.g., increased pulmonary function in asthma and decreased glucose levels in diabetes), enhanced immune function (e.g., increased natural killer cells in HIV and cancer), and enhanced alertness and performance (e.g., EEG pattern of alertness and better performance on math computations). Many of these effects appear to be mediated by decreased stress hormones." The University of Miami School of Medicine: Touch Therapy Institute

Voting Sheets

Senate ED&A Committee

EXECUTIVE SESSION

Bill # HB 1326

Hearing date: 4-26-10

Executive session date: 5-6-10

Motion of: OTP - Failed convert to ITL **VOTE:** 2-2

Made by Senator:	Cilley	☐	**Seconded by Senator:**	Cilley	☐	**Reported by Senator:**	Cilley	☐
	Fuller Clark	☐		Fuller Clark	☐		Fuller Clark	☐
	DeVries	☑		DeVries	☐		DeVries	☐
	Downing	☐		Downing	☐		Downing	☐
	Carson	☐		Carson	☑		Carson	☐

Motion of: ________________ **VOTE:** ______________

Made by Senator:	Cilley	☐	**Seconded by Senator:**	Cilley	☐	**Reported by Senator:**	Cilley	☐
	Fuller Clark	☐		Fuller Clark	☐		Fuller Clark	☐
	DeVries	☐		DeVries	☐		DeVries	☐
	Downing	☐		Downing	☐		Downing	☐
	Carson	☐		Carson	☐		Carson	☐

Committee Member	*Present*	*Yes*	*No*	*Reported out by*
Senator Cilley, Chairman	☑	☐	☑	☑
Senator Fuller Clark, Vice-Chair	☐	☐	☐	☐
Senator DeVries	☑	☑	☐	☐
Senator Downing	☑	☑	☐	☐
Senator Carson	☑	☐	☑	☐

***Amendments:** OTP BD
SC

Notes: ITL

Committee Report

STATE OF NEW HAMPSHIRE

SENATE

REPORT OF THE COMMITTEE

Date: May 6, 2010

THE COMMITTEE ON Executive Departments and Administration

to which was referred House Bill 1326

AN ACT relative to the use of long-term antibiotics for the treatment of Lyme disease.

Having considered the same, the committee recommends that the Bill:

IS INEXPEDIENT TO LEGISLATE

BY A VOTE OF: 2-2

AMENDMENT # s

Senator Jacalyn L. Cilley
For the Committee

Cathy Mullen 271-3067

New Hampshire General Court - Bill Status System

Docket of HB1326

Docket Abbreviations

Bill Title: relative to the use of long-term antibiotics for the treatment of Lyme disease.

Official Docket of **HB1326**:

Date	Body	Description
12/10/2009	H	Introduced 1/6/2010 and Referred to Health, Human Services and Elderly Affairs; **HJ 6**, PG.236
01/13/2010	H	==RESCHEDULED== Public Hearing: 1/28/2010 2:00 PM LOB 205 (Orig 10:00 AM)
01/20/2010	H	Executive Session: 2/2/2010 10:00 AM LOB 205
02/02/2010	H	Majority Committee Report: Refer to Interim Study for Feb 10 RC (vote 18-1); **HC 13**, PG.537
02/02/2010	H	Minority Committee Report: Ought to Pass; **HC 13**, PG.537
02/10/2010	H	Special Ordered to Beginning of Feb 17 Regular Calendar: MA Without Objection; **HJ 16**, PG.783
02/17/2010	H	Refer to Interim Study: MF DIV 135-218; **HJ 18**, PG.984-985
02/17/2010	H	Ought to Pass with Amendment (Rep Daniels); **HJ 18**, PG.985
02/17/2010	H	Floor Amendment #0574h (Rep Daniels) Adopted, VV; **HJ 18**, PG.985
02/17/2010	H	Ought to Pass with Amendment #0574h: MA **RC** 300-56; **HJ 18**, PG.984-987
02/17/2010	H	Reconsideration (Rep Daniels): MF VV; **HJ 18**, PG.987
03/24/2010	S	Introduced and Referred to Executive Departments and Administration; **SJ 11**, Pg.262
04/19/2010	S	Hearing: April 26, 2010, Room 206-208, LOB, 1:00 p.m.; **SC17**
05/06/2010	S	Committee Report: Inexpedient to Legislate, 5/12/10; **SC19**
05/12/2010	S	Inexpedient to Legislate, MF, VV; **SJ 18**, Pg.458
05/12/2010	S	Sen. Cilley moved Ought to Pass; **SJ 18**, Pg.458
05/12/2010	S	Sen. Cilley Floor Amendment 2045s, NT, Division 13Y-11N, AA; **SJ 18**, Pg.459
05/12/2010	S	Sen. Downing Floor Amendment 2064s, NT, AF, VV; **SJ 18**, Pg.460
05/12/2010	S	Ought to Pass with Amendment 2045s, NT, MA, VV; OT3rdg; **SJ 18**, Pg.460
05/12/2010	S	Passed by Third Reading Resolution; **SJ 18**, Pg.497
05/19/2010	H	House Non-Concurs with Senate AM and Req Comm of Conf (Rep Rosenwald): MA VV; **HJ 46**, PG.2195
05/19/2010	H	Speaker Appoints: Reps French, Merrick, Case & Cebrowski; **HJ 46**, PG.2195
05/19/2010	S	Sen. Cilley accedes to House Request for Committee of Conference, MA, VV; **SJ 20**, Pg.656
05/19/2010	S	President Appoints: Senators Gilmour, Kelly and Downing; **SJ 20**, Pg.656
05/21/2010	H	Conference Committee Meeting: 5/24/2010 11:00 AM LOB 205 ==Recessed==
05/24/2010	H	==Reconvene== Conference Committee Meeting: 5/26/2010 3:00 PM LOB 205 ==Time Change (Orig 2:00 PM)==
05/27/2010	S	Conference Committee Report 2253; Unable to Reach Agreement, Filed
06/02/2010	S	Conference Committee Report 2253; Adopted, VV; **SJ 21**, Pg.678
06/02/2010	H	Conference Committee Report #2253 Adopted, VV

NH House NH Senate Contact Us

New Hampshire General Court Information Systems
107 North Main Street - State House Room 31, Concord NH 03301

Other Referrals

COMMITTEE REPORT FILE INVENTORY

HB 1326 ORIGINAL REFERRAL ____ **RE-REFERRAL**

1. THIS INVENTORY IS TO BE SIGNED AND DATED BY THE COMMITTEE SECRETARY AND PLACED INSIDE THE FOLDER AS THE FIRST ITEM IN THE COMMITTEE FILE.
2. PLACE ALL DOCUMENTS IN THE FOLDER FOLLOWING THE INVENTORY IN THE ORDER LISTED.
3. THE DOCUMENTS WHICH HAVE AN "X" BESIDE THEM ARE CONFIRMED AS BEING IN THE FOLDER.
4. THE COMPLETED FILE IS THEN DELIVERED TO THE CALENDAR CLERK.

✓ **DOCKET (Submit only the latest docket found in Bill Status)**

✓ **COMMITTEE REPORT**

✓ **CALENDAR NOTICE on which you have taken attendance**

✓ **HEARING REPORT (written summary of hearing testimony)**

✓ **HEARING TRANSCRIPT** (verbatim transcript of hearing) [See File #2]
List attachments (testimony and submissions which are part of the transcript) by number [1 thru 4 or 1, 2, 3, 4] here: 1-23

✓ **SIGN-UP SHEET** (8)

ALL AMENDMENTS (passed or not) CONSIDERED BY COMMITTEE:

✓ - AMENDMENT # 1939s ____ - AMENDMENT # ____
✓ - AMENDMENT # 1940s ____ - AMENDMENT # ____

ALL AVAILABLE VERSIONS OF THE BILL:

✓ AS INTRODUCED ✓ AS AMENDED BY THE HOUSE
____ FINAL VERSION ____ AS AMENDED BY THE SENATE

✓ **PREPARED TESTIMONY AND OTHER SUBMISSIONS (Which are not part of the transcript)**
List by letter [a thru g or a, b, c, d] here: A, B

✓ **EXECUTIVE SESSION REPORT**

____ **OTHER (Anything else deemed important but not listed above, such as amended fiscal notes):**

IF YOU HAVE A RE-REFERRED BILL, YOU ARE GOING TO MAKE UP A DUPLICATE FILE FOLDER

DATE DELIVERED TO SENATE CLERK 9-14-10

COMMITTEE SECRETARY