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Matter which is either (a) all new or (b) repealed and reenacted appears in regular type.

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.

Amendments

Rep. Daniels, Hills. 6
January 28, 2010
2010-0359h
10/05

IF this amendment is adopted by the Committee, please deliver to the House Clerk (Room 317) or Senate Clerk (Senate Chamber), the 2 originals and 2 copies.

Amendment to HB 1326

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

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 long-term antibiotic therapy for therapeutic purposes to a person diagnosed with and having symptoms of Lyme disease if diagnosis and treatment 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 diagnosis and treatment has been documented in the physician's medical record for that patient. In this section:

I. "Long-term 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, pursuant to a clinical diagnosis that is based on knowledge obtained through medical history and physical examination alone, or in conjunction with testing that provides supportive data for such clinical diagnosis.

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.

Rep. Daniels, Hills. 6
January 28, 2010
2010-0359h
10/05

Amendment to HB 1326

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

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 long-term antibiotic therapy for therapeutic purposes to a person diagnosed with and having symptoms of Lyme disease if diagnosis and treatment 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 diagnosis and treatment has been documented in the physician's medical record for that patient. In this section:

I. "Long-term 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, pursuant to a clinical diagnosis that is based on knowledge obtained through medical history and physical examination alone, or in conjunction with testing that provides supportive data for such clinical diagnosis.

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.

Rep. Daniels, Hills. 6
January 28, 2010
2010-0359h
10/05

Amendment to HB 1326

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

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 long-term antibiotic therapy for therapeutic purposes to a person diagnosed with and having symptoms of Lyme disease if diagnosis and treatment 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 diagnosis and treatment has been documented in the physician's medical record for that patient. In this section:

I. "Long-term 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, pursuant to a clinical diagnosis that is based on knowledge obtained through medical history and physical examination alone, or in conjunction with testing that provides supportive data for such clinical diagnosis.

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.

Speakers

0

SIGN UP SHEET

To Register Opinion If Not Speaking

Bill # HB 1326 Date 1/28/2010

Committee HHS

**** Please Print All Information ****

Name	Address	Phone	Representing	(check one) Pro	Con
~~Arlene Stappe~~	~~Ashland NH~~	~~603-968-4478~~		✓	
Virginia Williams	Greenfield NH	603-547-3231		✓	
Whitney Williams	Manchester NH	6037312957		✓	
Penny Demos	Bedford NH	471-1260		✓	
MARIE POIRIER	MANCHESTER, NH 03103			✓	
Deborah Hemeon	Barrington, NH 03825			✓	
DEBORAH Rondeau	LEBANON ME		/ Business Treated Owner NH	✓	
Nancy DeMarco	Mason, NH	/ 878-4776		✓	
Estelle Playdon	Dunbarton, NH	774-4861		✓	
[illegible]		1603-533-9676		✓	
Carol Golubiewski		938-5136	Bradford	✓	
Sarah Golubiewski				✓	
Ben Golubiewski	Bradford, NH	938-5136		✓	
Rachel Golubiewsk				✓	
Jeremy Golubiewsk				✓	
Patrick Fallon		603269-2298	Strafford	✓	
MARK Longley	CONCORD NH	229-1979		✓	
Saengjan Longley	Concord NH	229-1979		✓	
Gail Beers	Amherst, NH	603-673-9544		✓	
Karen Condylis	47 Oriole Dr NH			✓	
Krista Passin	3 Gold St NH	(603) 595-4579		✓	
Mark [illegible]	91 Rollins Rd Rollinsford NH	# 749-6494		✓	
CHARLES CONVERSE	19 MARSTON ST. MAN. 03102	623-7096		✓	

SIGN UP SHEET

To Register Opinion If Not Speaking

Bill # HB 1326 Date 1/28/2010

Committee [illegible]

** **Please Print All Information** **

Name	Address	Phone	Representing	(check one) Pro	Con
JAMES R KALLOCH	252 PEMBROKE HILL RD.	485-1944		✓	
Kevin D. Madison	84 Ridge Rd, NORTHWOOD	942-5834		✓	
Terri Madison	84 Ridge Rd Northwood	942-5834		✓	
Hank Amsden	5 Wilfred Ave Concord	224-1741		✓	
Jean Amsden	5 Wilfred Ave Concord	224-1741		✓	
REP. NAIDA KAEN	Strafford 7, Lee, Durham Madbury			✓	
WAYNE Boyant	37 Gamecrest st Manchester NH			✓	
William Wurst	21 Danbury Circle Amherst, NH	673-4021		✓	
Pauline E Dawson	14 Woodbury Ln Boscawen NH			✓	
John SIAS	43 North Pepperell Rd Hollis			✓	
Richard Moore	27 Bedford Center Rd Bedford			✓	
Lauren Hurley	28 Bela View DR, Bow	16032239742		✓	
Mitchell [illegible]	47 Oriole Dr., Bedford, NH			✓	
FREDERICK J. MITT II	45 ROY STREET, NASHUA NH			✓	
Douglas R Newton	83 Newmarket Rd WARNER NH				

SIGN UP SHEET

To Register Opinion If Not Speaking

Bill # #B1326 Date 1/28/2010

Committee HHS

**** Please Print All Information ****

				(check one)	
Name	Address	Phone	Representing	Pro	Con
Edward A Thurston	51 Newton Rd Plaistow NH			✓	
		603-382-6277			
Marie Veselsky	PO Box 606 Plymouth NH				
		603-536-3513		✓	
Ulla Jurrissen	24 Pocahontas Rd Kittery Pt ME	207-439		✓	
JAN JURRISSEN	24 POCAHONTAS Rd Kittery Pt ME	207 439-0922 0922		✓	
Jessica Hughes	34 Herseystreet Bedford	645-1353		✓	
Jake Wojenski	17 Oriole Dr. Bedford	472-2796		✓	
Lisa Wojenski	17 Oriole Dr Bedford	4722796		✓	
VALERIE PETERSON	19 WEBSTER CT MERRIMACK	361-6043		✓	
LOIS TOURANGEAU	37 DONGUAN CT MERRIMACK	424-0417		✓	
June Cormier	183 Critchett Rd Candia NH	483-5773		✓	
Jeff Shagory	29 Apple Ln Unit D Hollis NH	465-2855		✓	
Amy Simoneau	P.O. Box 290, Hollis, NH 03049	582-8481		✓	
Pamela Ray	29 Sullivan St Nashua	6033980142		✓	
Dal J Ray	1 New Hampshire Ave	6038604845		✓	
Marilyn Rivera	28 Aspen Dr.	664-7928	NHLyme.org	✓	
PAMELA BROWN	2 CLOCKTOWER PL NASHUA	603-521-7253		✓	
Carol Batchelder	4 Country Club Dr Apt 34 Manchester, NH			✓	
Chelli Tennis	17 Robin Hood DR. Nottingham NH			✓	
Mary Fanslau	14 Old Ridge Rd Strafford		NHLyme Chairman	✓	
Vicki Flint	12 Bohannon Bridge Road Brookline NH			✓	

SIGN UP SHEET

To Register Opinion If [✓ Not Speaking]

Bill # HB 1326, Date 1/28/2010
Committee WRS

**** Please Print All Information ****

Name	Address	Phone	Representing	(check one) Pro	Con
Lisa Brady	317 South Rd	483 5612		✓	
Brianna Morin	317 South Rd	483-5612		✓	
Molly Brady	317 South Rd	483-5612		✓	
Rep Carla Skinder			Sullivan 1	✓	
Gina Balkus	Lebanon	629-1286	Dartmouth-Hitchcock		✓
Yvonne Nanasi	41 Briar Rd Bedford, NH		Dog Owners of the Granite State.	✓	
Rep R.B. Dick Drisko				✓	
Rep Suzanne Smith			Env + Ag.	✓	
Shari Wales	21 McGettigan Rd. Milford	673-7275		✓	
[illegible]	2 Mack H. Hill Rd Amherst NH	603 673 5777		✓	
Marie Stanger	35 Town Farm Rd New Boston			✓	
Janice [illegible]	119 Danes PK Rd Goffstown	487-5528			
Leona Mabry	7 School St., Unit #105 Bennington, NH 03442				
Howard Mabry	" " " "	603-588-6786		✓	
David J Day Jr	311 Circle Rd Manchester NH 03103	603 821 4502		✓	
[illegible]	[illegible] Bow, N.H. 03304			✓	
BOB DUDRA	90 OLD DUBLIN RD HANCOCK			✓	
Rep Carol Vita	MIDDLETON, NH	755-9700		✓	
Lisa Smith	15 Flint Meadow Dr. Brookline 03033			✓	
Aileen Landis	61 McAfee Farm Rd Bedford NH 03110			✓	
LINDA MENZE	28 KRZYCANIAK G Contoocook 03229			✓	
GERALD SMITH	45 CLINTON ST CONCORD NH			✓	
Kerri Dexter	81 Union Rd, Northfield NH 03276			✓	

SIGN UP SHEET

To Register Opinion If [✓ Not Speaking]

Bill # HB 1326 Date 1/28/2010
Committee HHS

**** Please Print All Information ****

Name	Address	Phone	Representing	(check one)	
				Pro	Con
Megan Kettmann	Bow, NH	225-7016		✓	
Cathy Kettmann	Bow, NH	225-7016		✓	
Laura Grandis	7 Narragansett Amherst, NH	236-9892		✓	
Madilyn Civiello	7 Narragansett Amherst NH	2499506		✓	
Mitchell Hale	47 Mack Hill rd. Amherst, NH	673-9687		✓	
Gwen Hale	47 mack hill RD Amherst NH	801-3748		✓	
Melinda Rosen	PO BOX 4484 Portsmouth	897-5892		✓	
Sandra mcLean	51 Hillcrest Dr. - Laconia NH	528-2172		✓	
Karen Dudra	90 Old Dublin Rd Hancock	525-4631		✓	
Maureen Hodges Else	PO BOX 8			✓	
Megan + Brendan Ryder	307 Pleasant St Concord NH	226-7989		✓	
Don McNeel MD	25 WAYSIDE FARM LANE HAMPTON, NH			✓	
Teresa Rosenberger	43 N Main	226-1000	Naturopathic Doctors	✓	
Sheri Stickney	43 Barrington Dr. Bedford NH	488-5406		✓	
CHERYL ANN VICTOR	289 WINDING POND RD, LONDONDERRY, NH	432-1505		✓	
James De Marco	Mason, NH	878-4776		✓	
CHRIS HERD	Sunapee, NH	763-9561		✓	
Rep. Tim Butterworth	Chesterfield, NH 03443	363-8076		✓	
Dr. Donald F. Bent, Health Officer	P.O. Box 32 New London, NH 03257	526-4761		✓	

SIGN UP SHEET

To Register Opinion If Not Speaking

Bill # HB1326 Date 1/28/10

Committee HHS

**** Please Print All Information ****

Name	Address	Phone	Representing	(check one)	
				Pro	Con
Kristine Hanson	40 Rangeway Dunbarton	774-3764		✓	
Melissa Benson	10 Hardy Rd. Ports.	603436646		✓	
Glenn Hayer	Barrington	6646960		✓	
Peggy Flanagan	7 Cailey Anna Ln Dover, NH 03820	749-9819		✓	
Carol Reynolds	Strafford			✓	
Susan Tufts-Moore	277 Bedford Center Rd. Bedford			✓	
* Catherine McLaughlin-Hills CNM MSN	135 Piscataqua Rd			✓	
(603) 682-9168	Durham, NH 03824				
please call me !!!					

SIGN UP SHEET

To Register Opinion If Not Speaking

Bill # HB 1326 Date January 28, 2010

Committee Health and Human Services Committee

**** Please Print All Information ****

Name	Address	Phone	Representing	(check one) Pro	Con
Laura Schwartz	102 Winnicutt	7750021		✓	
Mark Cantrell	Stratham 28 Glance Rd 03087	603-722-0227		✓	
Gayle Cantrell	"	"	"	✓	
Warren Hyde	363 Deerfield Rd Candia, NH.	603 483-0667		✓	
Unai Garabieta	31 Boutwell St Wilmington Ma	978-657 4146		✓	
Gary Fowler	19 Sunny Oak Ter Strafford NH 03884			✓	
Donna Poirier	173 Pine Hill Rd Weare NH	603-529-2989		✓	
Nancy Sampo	68 Woodhill Hooksett Rd Bow	225-1043		✓	
Bonnie O'Keefe	41 River Rd. Stratham, N.H.	603-772-2748		✓	
Kim Schillereff	111 Chester Rd Raymond	895-6265		✓	
Beverly Geyer	28 Bela View Dr Bow NH	223-9742		✓	
Helen Ballou	PO Box 289 Brookline NH 03033			✓	
Peter Ballou	" " " " "			✓	

Hearing
Minutes

HOUSE COMMITTEE ON HEALTH, HUMAN SERVICES AND ELDERLY AFFAIRS

PUBLIC HEARING ON HB 1326

BILL TITLE: relative to the use of long-term antibiotics for the treatment of Lyme disease.

DATE: January 28, 2010

LOB ROOM: 205 **Time Public Hearing Called to Order:** 1:59 PM

Time Adjourned: 7:13 PM

(please circle if present)

Committee Members: Reps. [✓ Rosenwald], [✓ Donovan], [✓ French], [✓ Schulze], Tilton, [✓ Butcher], [✓ Bridgham], E. [✓ Merrick], T. [✓ Russell], DiPentima, Miller, Batula, C. [✓ McMahon], [✓ Pilliod], [✓ Emerson], [✓ Case], Millham, Wells, [✓ Cebrowski] and [✓ Kotowski].

Bill Sponsors: Reps. Daniels, Hills 6; Vita, Straf 3

TESTIMONY

* Use asterisk if written testimony and/or amendments are submitted.

***Representative Gary Daniels, prime sponsor – supports.** See written testimony. He introduced the bill with an amendment 0359h. New Hampshire has the largest amount of cases. Rockingham, Strafford, Hillsboro Counties. New Hampshire people are forced to travel outside our borders for treatment. Allows long term treatment without disciplinary measures against doctors. "Under our Skin" is to be show on 1/29/2010 in Room 305. There are now two standards of treatment.

David Hunter, Bedford, NH – supports. The medical community is divided as to how to treat this disease. This bill allows doctors to treat Lyme disease. Connecticut had a similar bill passed. We desperately need doctors to be free to treat Lyme disease for more than four weeks. Thee is chronic Lyme disease. We desperately need this bill. It is infectious not contagious. IDSA's authority has caused hardship to get treated and diagnosed properly. They said they have the right message. New Hampshire has surpassed Connecticut and New York in the number of cases. New England is an epicenter. He facilitates a support group. In other states doctors are under severe pressure and we want to prevent a problem for doctors in New Hampshire. We don't have a specific situation in New Hampshire. I can't answer regarding a doctor receiving such a privilege for another disease.

Janet Monahan, New Hampshire Medical Society – opposes. They oppose this bill because it is not necessary. Doctors follow standards. This particular disease should not have an exemption. The Board of Medicine doesn't track medication.

***Greg Kettman, on Lyme Board – supports.** See written testimony. He is on the board that put this together. His wife has Lyme disease that started 5 years ago. She was crippled but can walk together. She asked her doctor for care for Lyme disease and was denied. Her doctor is in New

York. This gentleman referred us to the loose leaf book with information. His wife's original doctor sent a note dismissing her from his practice.

***Don McNeel, M.D., Board Certified Family Practice since 1998 – supports.** See booklet. He is currently at Wentworth Douglas Hospital. He's amazed the debate is there. He should be able to treat patients as necessary. It wasn't until I started treating Lyme disease that the politics of this impacted him. I do not currently treat patients with chronic Lyme disease. This bill will help families to get proper treatment for patients. Connecticut took away the reporting of cases.

***Dr. Young, Board Member of Northeast Healthcare Quality Foundation – supports.** See written testimony. He talked about his daughter who had episodes of blindness and has had 9 ½ years of antibiotics. The care of a patient should be determined by physicians. Lyme germ hides. It also hides when a person is cured. The people in this room are treatment failures. T is expensive. Practice defensive medicine. He has concerns regarding potential problems for doctors treating Lyme disease. Feels comfortable using either standard for treatment. There are different diagnostic and treatment philosophies. The CDC doesn't believe there is chronic Lyme disease. I am dealing with the issue of Lyme disease.

***Susan Saviteer, M.D., IDSA & NH Medical Society – opposes.** See written testimony. IDSA – infectious disease throughout the country. ISDA sets guidelines they put together carefully.

Chronic Lyme disease:

1. Diagnosis with Lyme.
2. Continued subjective symptoms.
3. Symptoms started 6 months into disease.

Patients treated with placebos and antibiotic had the same outcome. Long term treatment with antibiotics allows some other germs to grow. The current bill will not change the practice of medicine. Physicians must maintain their knowledge and continue to encourage them to be open minded. Yes, she has heard of alternative providers being sought. SSDA sets guidelines and doesn't expect major changes. She doesn't see where a physician would be reprimanded for using a particular protocol.

***Marie Veselsky, Dietician – supports.** See written testimony. This has not been a fun disease for me. It took 9 months to be negative. She had many disturbing symptoms. She figured out she had Lyme disease. She is able to run again and celebrates every day of life. She was on antibiotics for 8 months.

***Jacqueline Arlen, Hampstead, NH – supports.** See written testimony. She is here with daughter Victoria in a wheelchair. Her symptoms were classic, but missed by her physician.

***June Cormier, Candia, NH – supports.** See written testimony. She had difficulty securing treatment.

***Jessica Wojenski, Bedford, NH – supports.** See written testimony. She is a senior in high school and sought long term treatment and has gotten her life back. She rotates antibiotics every two months.

***Karen Dudra, Hancock, NH – supports.** See written testimony. She developed neurological symptoms. After three months of treatment sought an ILAD doctor and had 9 months of treatment.

Today she has her life back. A nurse practitioner, the right lab, and a doctor restored her health. Protect our Lyme literate doctors.

***Carl Tuttle, Hudson, NH – supports.** See written testimony. The bill should include nurse practitioners.

***Laura Grandis, Amherst, NH – supports.** See written testimony. Doctors must not be fearful of how they treat. They must be able to use long term therapy. Without antibiotics her symptoms return as bad as when they first started.

***Erin Fallon, Strafford, NH – supports.** See written testimony. Has term chronic Lyme disease. She feels blessed to be here today. Her children have had symptoms. She has neurological damage. She knows her insurance is looking at her family.

***Julie Hall, Kensington, NH – supports.** See written testimony. She and three of her children have had Lyme disease. She lives in Kensington where a high rate of Lyme disease is found. Her oldest son was severely affected, today he is skiing after a longer course of antibiotics. Doctors need to be open to new studies. She spent $5,000 a month when insurance ended.

***Marilyn Rivera, Strafford, NH – supports.** See written testimony. She has Lyme disease and may have passed it on to her daughter. Her daughter has been on antibiotics for two years.

***Andrea Martel, Bedford, NH – supports.** See written testimony. She has had cognitive issues. In a month she will have been on antibiotics for one year.

***Edwad Yourtee, M.D., Windham, NH – opposes.** See written testimony. Medical treatment should not be legislated. No new data says there is no scientific data showing long term treatment works. There have been deaths particularly with the use of long term I.U.S. The standards of care ISDA standards are based on science. ILAD are based on opinion/published studies do not demonstrate that long term therapy works. CDC doesn't list ILAD guidelines. The Borrelia tick is migrating to the southern part of the state. A different species is found in Europe. Europe has a more virulent strain. Elisa and Weston Blat are tests to identify Lyme disease. Elisa is the Lyme titre test. Insurance companies rely on ISDA guidelines and may not allow payment for other therapy.

***Karen Steele, Atkinson, NH – supports.** See written testimony. She is a mechanical engineer who was diagnosed 3 ½ years ago. In her neighborhood 50% of the houses in the neighborhood have a person with Lyme disease. Dr. Kalish at Tufts saw her and said she didn't have Lyme disease and should go see a psychologist. She has been unable to find a doctor to treat her with long term antibiotics.

***Doublas Newton, Warner, NH – supports.** See written testimony. 40% of the patients don't meet CDC diagnosis. Who has Lyme? Who is going to treat it?

***Peggy Flanagan, Dover, NH – supports.** See written testimony. She related the story of her daughter's problem with Lyme disease. The Lyme specialist needed the cooperation of the family physician.

***Jonathan Golvbiewski, Bradford, NH – supports.** See written testimony. He has received very expensive care. He is totally disabled. His wife has it as well as four children all with Lyme disease. Corruption is a consideration.

***Arlene Stoppe, Ashland, NH – supports.** See written testimony. Has a wide range of symptoms. She thinks insurance companies are going after doctors.

***Laura Piazza Herd, Sunapee, NH – supports.** See written testimony. The doctors put themselves at risk.

Joanne Antonia, Dunbarton, NH – supports. She had difficulty finding doctors to treat her. Over 50% of ticks in New Hampshire are infected. Doctors are afraid. I have been there and worse. The problem is with children, young adults and all are going to become chronically ill. The University of Connecticut will test ticks for Lyme disease. The citizens of New Hampshire are not getting treated properly. We need this bill. It will give permission to doctors to treat us. It will cost more not to pass it.

***Julie Sanders, Manchester, NH – supports.** See written testimony. She was six years undiagnosed. Doctors should be able to treat us.

William Wurst, Amherst, NH – supports. He liked outdoor activities. The root cause is the insurance companies.

Cherylann Victor, Londonderry, NH – supports. She has Lyme disease and got it in 1967. She believes she has been bitten several times.

***Robert Furness, D.V.M., Apple Tree Animal Hospital – supports.** See written testimony.

Respectfully submitted,

Rep. Joan Schulze

Representative Joan Schulze, Clerk

HOUSE COMMITTEE ON HEALTH, HUMAN SERVICES AND ELDERLY AFFAIRS

PUBLIC HEARING ON HB 1326

BILL TITLE: relative to the use of long-term antibiotics for the treatment of Lyme disease.

DATE: 1/28/2010

LOB ROOM: 205 **Time Public Hearing Called to Order:** 1:59 PM

Time Adjourned: 7:13 pm

(please circle if present)

Committee Members: Reps. [✓ Rosenwald], [✓ Donovan], [✓ French], [✓ Schulze], Tilton, [✓ Butcher], [✓ Bridgham], [✓ E. Merrick], [✓ T. Russell], DiPentima, Miller, Batula, [✓ C. McMahon], [✓ Pilliod], [✓ Emerson], [✓ Case], Millham, Wells, [✓ Cebrowski] and [✓ Kotowski.]

Bill Sponsors: Reps. Daniels, Hills 6; Vita, Straf 3

TESTIMONY

* Use asterisk if written testimony and/or amendments are submitted.

* Rep. Gary Daniels prime sponsor introduced the bill with an amendment 0359h.
N.H. largest amt. of cases Rockingham, Strafford, Hillsboro County
N.H. are forced to travel outside our borders for treatment
Allows long term treatment without disciplinary measures against doctors.
"Under our Skin" to be shown 1/29 in room 305
There are now 2 standards of treatment

David Hunter. medical community is divided as to treat this disease. This bill allows doctors to treat Lyme disease. Conn. had a similar bill passed.
Disparately need doctors to be free to treat Lyme disease for more than 4 weeks. There is chronic Lyme disease
We dEsparately need this bill
It is infectious not contagous. IDSA's authority have caused hardship to get treated & diagnosed properly
CDC is boss

They said they have the right message. NH. has surpassed Conn. ②
& N.Y is number of cases. New England is an epi center.
He facilitates a support group. In other states doctors are under
severe pressure and we want to prevent a problem for doctors
in N.H. We don't have a specific situation in N.H. I can't answer
Re: a doctor receiving such a privilege for another disease "
Not aware

Janet Monahan. NH Medical Society opposes this bill because
it is not necessary. Doctors follow standards. This particular
disease should not have an exemption
Bd of Medicine doesn't teach medication

☆ Greg Kettmann on Lyme Board that put this together, My wife
has Lyme disease started 5 years ago. She was crippled she can walk
together. She asked doctor for care for Lyme disease & was denied. Her
doctor is in N.Y. This gentleman referred us to the loose leaf
book with information. Please SEE written testimony.
The wife's original doctor sent a note dismissing her from his
practice.

Dr. Dan McKeel Board Certified Family Practice since 1998 currently at
Wentworth Douglas Hospital. Amazed the debate is there. Should
be able to treat patients as necessary It wasn't until I started
treating Lyme Disease that the politics of this impacted him.
I do not currently treat patients with chronic
Lyme disease. This bill will help families to get
proper treatment for patients. Conn. took away
the reporting the cases

Dr Young. N.E. Quality Foundation President Supports
☆ Supports the bill. Talked re daughter who had episodes
of blindness has 9½ years of antibiotics. Care of patient
should be determined by physician. Lyme germ hides
It also hides when ~~it is~~ person is cured. The person in
this room are treatment failures. It is expensive.
Practice defensive medicine. Concern re: potential
problems for doctors treating Lyme disease
Feel comfortable using either standard for treatment
Different diagnostic & treatment philosophies

HB 1326 continued 1/28/2010

CDC doesn't believe there is chronic Lyme disease

I am dealing with the issue of Lyme Disease

Susan Saviteer M.D. IDSA, NH. Medical Society

opposes this bill

IDSA - Infectous Docs. thraughout the country

ISDA sets guidelines put together carefully

Chronic Lyme Disease. 1- dx c̄ Lyme

2- continued subjective symptoms

3. symptoms started 6 months into disease

Placebo treated + antibiotic treated patients had same outcome

Long term treatment with antibiotics allow some other germs to grow

The current bill will not change the practice of medicine

Physicians must maintain their knowledge & continue to encourage them to be opened minded.

Yes - have heard of alternative providers being sought.

ISDA sets guidelines don't expect major changes

Don't see where a physician would be repimanded for using a particular protocol.

Marie Veselsky. reg. dietican

This has not been a fun disease for me. It took 9 months to be negative. Had many disturbing symptoms. She figured out she had Lyme Disease

HB1326 continued

Marie Veselsky.
Is able to run again. I celebrate every day of life.
Was on antibiotics 8 months.

Jacqueline Arlen. with daughter Victoria in a wheelchair Her symptoms were classic, but missed by physician

June Cormier Supports the bill
Had difficulty securing treatment

Jessica Wojenski supports the bill
a senior in high school saught long term treatment and has gotten her life back.
Rotates antibiotics every 2 months

Karen Dudra supports the bill
Developed neurological symptoms. after 3 months of treatment saught an ILAD doctor had 9 months of treatment Today I have my life back. A nurse practitioner, right Lab, doctor restored by health - protect our Lyme literate doctors

Carl Tuttle supports the bill.
should include nurse practitioners

HB 1320 continued

☆ Laura Grandes supports the bill
Doctors must not be fearful of how they treat
They must be able to use long term therapy
Without antibiotics her symptoms return as bad
as when first started

☆ Erin Fallon - Has term chronic Lyme Disease
Feels blessed to be here today. Her children have
had symptoms - She has neurological damages
Knows her insurance is looking at her + her family

☆ Julie Hall - She + 3 children have $^{\text{had}}$ Lyme Disease
Lives in Kensington where a high rate of Lyme
Disease is found. Oldest son was severly
affected, today he is skiing after a longer
course of antibiotics
Doctors need to be open to new studies
Spent $5000 a month when insurance ended

☆ Marilyn Rivera - has Lyme disease and
may have passed it to daughter
Daughter has been on antibiotics for 2 years
Supports the bill

Andrea Martel - Supports HB 1320
cognitive issues difficult
In a month on antibiotics for one year

HB1326 continued

Edward Yaurtee M.D. representing himself
opposes this bill
Medical treatment should not be legislated.
No new data says there is no scientific data showing long term treatment works
There have been deaths particularly using long term I.V.s.
Two standards of care ISDA standards are based on science ILAD are based on opinion / published studies do not demonstrate that long term therapy works CDC doesn't list ILAD guidelines
The Borrelia tic is migrating to so. part of state
A different species is found in Europe. Europe has a more virulent strain
~~Elza~~ Elisa & Weston Blot are tests to identify Lyme ~~tes~~ disease Elisa is the Lyme titre test.
Insurance companies rely on ISDA guidelines and may not allow payment for other therapy.

Karen Steele . a mechanical engineer
diagnosed 3½ years ago In her neighborhood
50% ~~eighty~~ houses in neighborhood have person with Lyme Disease
Dr. Kalish at Tufts saw her said ~~to~~ she didn't have Lyme disease should go see a psychologist Has been unable to find a doctor to treat her with long term antibiotics
Supports

HB 1320 cont. ⑦

Douglas Newton Supports this bill
40% patients don't meet CDC diagnosis
Who has Lyme?
Who is going to treat it?

Peggy Flanagan Supports the bill
Related story of daughter's problems with Lyme Disease
The Lyme specialist needed the cooperation
of family physician

Jonathon ~~GowBlewski~~ GOLVBIEWSK
Supports the bill
Has received very expensive care
Totally disabled Wife has it as well has 4
children ~~youngest twins have Lyme~~ all with
Lyme disease
Corruption is a consideration

Arlene Stoppe Supports this bill
Has a wide range of symptoms
Thinks insurance companies are going after doctors

Laura Piazza Herd Supports this bill
The doctors put themselves at risk

Jeanne Antonia Supports this bill
Had difficulty finding doctors to treat her
Over 50% of ticks in N.H are infected
Doctors are afraid
I have been there and worse
The problem is with children, young adults are all going to become chronically ill
University of Conn. will test tics for Lyme Disease
The citizens of N.H. are not getting treated properly
We need this bill. It will give permission to doctors to treat us - It will cost more not to pass it

David Bourassa - not here

☆ Julie Sanders supports this bill
Has 6 years undiagnosed
Doctors should be able to treat us

William Hurst Supports this bill
Liked outdoor activities
Root cause is the insurance companies

Cherylann Victor Supports this bill
I have Lyme Disease got it in 1967. Believe I have been bitten several times

HB 1326 continued

Peter & Helen Ballou   Supports this bill
We need Lyme Disease Legislation

Susan Patterson Supports the bill
I had a tick on me for 4 days
Had to go out of state for treatment
Developed neuralogical symptoms and then it went to my brain
The doctor who was able to help her closed his practice
After 2½ yrs of antibiotics finally feeling better
Doctor has been told his peers are watching him
A U.S. gov't Web site compares the 2 treatment regimes

Catherine McLaughlin Hill   Supports the bill
Had fever, flu like symptoms, knee pain, etc.
Infusing I.V. antibiotics for a year
CDC Guidelines are not appropriate
We need legislation

Deborah Hemeon
Supports this bill
Was first diagnosed with fibromyalgia
It can passed through blood
Passes to children from Mother
Persons c̄ alzheimers sometimes can have a Lyme Disease base   Birds & Rodents also carry the ticks

Georgina Susan Messer   Supports this bill

ditto what other people have said

Dec 2008, was diagnosed was put on doxi until she could find a Lyme doctor. Found a doctor who never saw her because she (the doc) was sanctioned.

Expenses were out of pocket because found a doctor out of state

Doing much better after being put on a cocktail of meds.

We are going through what we went through with AIDs 20 years ago

We want the doctors to treat with long term therapy

Patrick Fallon

4/2005 diagnosed Mom has Lyme Disease probably got it from her. Has had symptoms all his life. Was on meds. 2 years felt better started college got depressed and has withdrew all but one class. No cure known. Doesn't remember childhood, school Please consider this bill

Thank you

David Hunter

We don't want to legislate care

Massive politics. Asking for doctors to be able to treat. Life is being destroyed at an unbelievable rate

Testimony

Rep Gary Daniels

HB1326

WHY NEW HAMPSHIRE NEEDS HOUSE BILL 1326

House bill 1326 is an act related to the use of long-term antibiotics for the treatment of Lyme disease. The bill authorizes licensed physicians to prescribe long-term antibiotics for therapeutic purposes to patients diagnosed with Lyme. HB 1326 protects physicians' rights to determine the most appropriate treatment protocol for their patients based on individualized clinical evaluation.

New Hampshire currently has the highest incidence of Lyme disease in the United States.
Source: Centers for Disease Control, 2009

Rockingham, Strafford and Hillsborough counties report the highest number of Lyme disease cases in the state. In 2007, more than 50 percent of the ticks tested in these counties were infected with the bacteria that causes Lyme, putting residents in those counties at greater risk of contracting Lyme.
Source: NH Dept. of Health and Human Services

Many New Hampshire residents suffer on-going neurological and physical effects from Lyme disease that make it difficult or impossible for them to work, drive or continue life as they once knew it. The long-term cost of Lyme disease to families, school systems, the health care system and the economy is astounding. According to a study published in 1993 in *Contingencies,* an actuarial trade publication, the average treatment and diagnosis and lost wages related to Lyme disease was $61,688 per year per patient.
Source: Lyme Disease Association

Children are in the highest risk category for contracting the disease, representing 25 percent of the total reported cases. A CDC study indicates that children with chronic Lyme in one state have a median school absence of 140 days. Columbia University reports that children suffering from chronic Lyme see significant drops in IQ as a result. Scores of New Hampshire students diagnosed with Lyme are currently on Section 504-plans and IEPs to help them maintain their school work despite lengthy absences. Many miss months and years of school.
Source: Centers for Disease Control, Columbia University, NH Testimony

Background

There are currently two standards of treatment for Lyme disease, though New Hampshire's Health and Human Services' website links to only one. **The Infectious Disease Society of America (IDSA)** characterizes Lyme disease as primarily acute and treated successfully in the vast majority of cases with, at most, a few weeks of antibiotics. **The International Lyme and Associated Diseases Society (ILADS)** asserts that Lyme *can* be chronic and its doctors determine the duration of treatment based on *individualized* clinical evaluation. Both ILADS and IDSA viewpoints are reflected in peer reviewed "evidence-based" guidelines.

When more than one standard of care exists, the critical question becomes who decides the appropriate course of treatment for the patient. The New Hampshire Department of Health and Human Services only links to the IDSA guidelines, limiting public healthcare choice to one option. Under the medical ethical principle of autonomy, the treatment decision belongs to the patient. The American Medical Association (AMA) 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.

A challenging political climate has translated into medical board actions against physicians nationwide for prescribing long-term Lyme disease treatment (ILADS vs IDSA guidelines). This has had a chilling effect on the number of Lyme-literate physicians who are trained and/or are willing to treat this complicated disease. As a result, New Hampshire residents—and those around the country—get sicker.

If Lyme disease is left untreated or not treated aggressively, it can have far-reaching implications—not only for patients' health, but also for healthcare costs, disability compensation and worker productivity. These costs far exceed the expense of paying for therapeutic antibiotics to treat the infection and its symptoms.

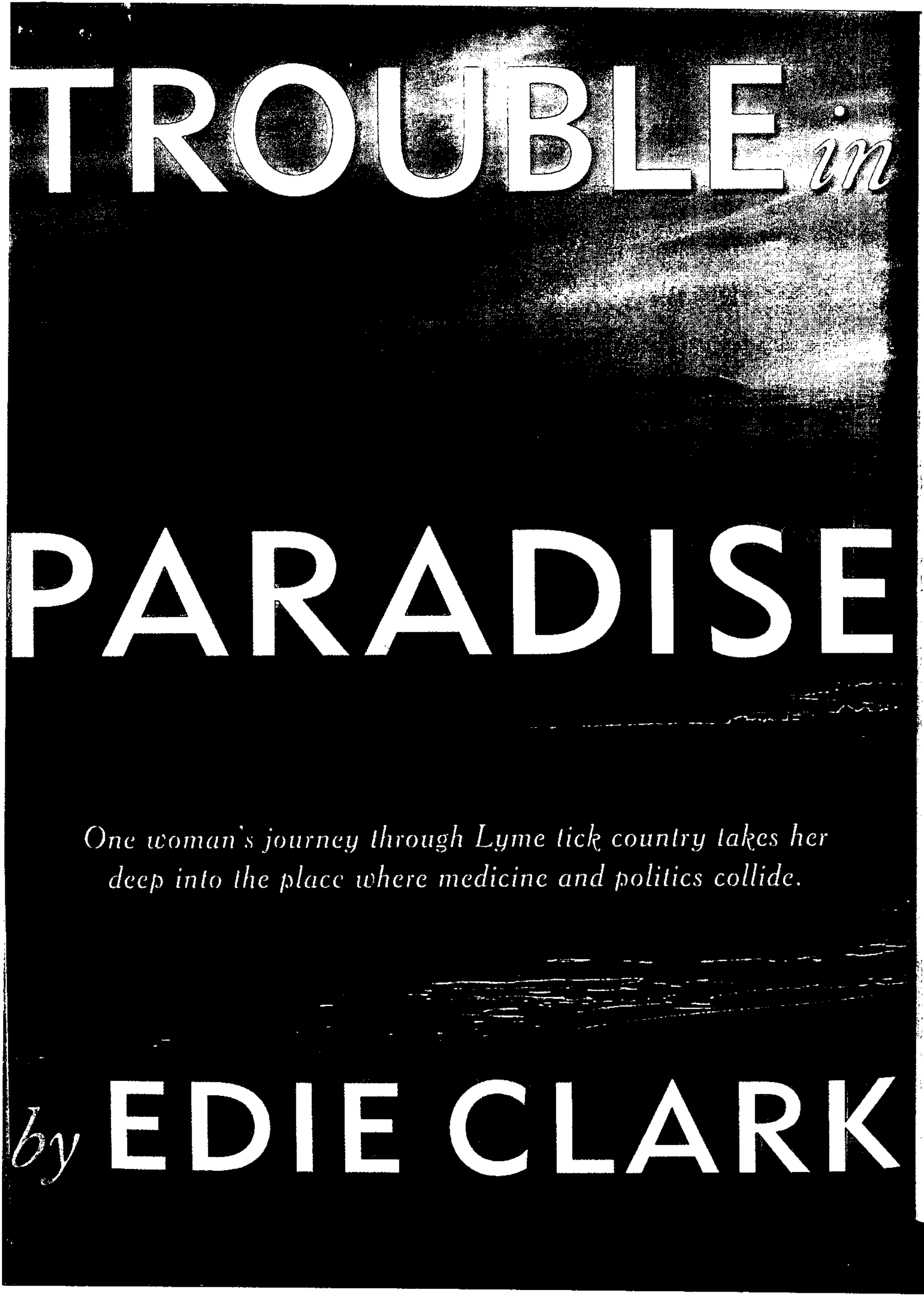
Many of New Hampshire's sickest residents travel across state borders to find physicians who are able and willing to treat Lyme disease based on individualized clinical evaluation. New Hampshire families need to ensure that physicians, insurers, patients and governmental agencies understand that **two** treatment approaches exist, and that physicians should be free to provide long-term antibiotic treatment when deemed clinically necessary.

House Bill 1326 does not legislate treatment. This bill contains language that will protect New Hampshire licensed Lyme-treating physicians from prosecution by the New Hampshire Board of Medicine solely on the basis of a clinical diagnosis and/or treatment of long-term Lyme disease. It allows a physician to prescribe, administer or dispense long-term antibiotic therapy to patients clinically diagnosed with Lyme or tick-borne diseases. It specifies that the Board of Medicine shall not initiate disciplinary action against a licensed physician solely for prescribing, administering or dispensing long-term antibiotic therapy to a patient clinically diagnosed with Lyme.

The single most important aspect of this legislation is that a physician can treat with antibiotics for more than four weeks without the fear of disciplinary action; a treatment that has been approved by ILADS physicians and will provide necessary care for scores of New Hampshire residents afflicted with Lyme disease. **This law will be a relief to New Hampshire families** who will finally be able to receive care in the Granite State; it offers hope that more physicians who are knowledgeable about Lyme disease will be encouraged to practice within the state of New Hampshire.

Please support New Hampshire House Bill 1326. We thank you in advance for your willingness to give thoughtful consideration to this serious health concern that affects so many of your constituents.

Representative Gary Daniels, Hillsborough 6, Sponsor
Representative Carol Vita, Strafford 3, Co-sponsor
The New Hampshire Lyme Legislation Committee



TROUBLE *in* PARADISE

One woman's journey through Lyme tick country takes her deep into the place where medicine and politics collide.

by EDIE CLARK

Oppos
shoreli
idyllic
to expe
illness,
Above:
prolific
male sh
cation)
Female
0.1 inc
smaller
half tha
size of
carry th

PORTRAIT PHOTOGRAPHS BY DANA SMITH

IN JULY 2002, HAVING SPENT AN IDYLLIC WEEK'S VACATION on one of the Elizabeth Islands off Cape Cod, I came home to New Hampshire. The island—a glorious, wild place marked by ancient beech forests, kettle ponds, and open grasslands—is also crawling with ticks, which at the time seemed only a minor obstacle to enjoying the abundant gifts it offers. Within a month of my return, however, I would begin to learn a bitter lesson—in the history, ethics, and politics of a debilitating disease, and the mystery that has surrounded it for more than 50 years.

LIKE MANY OTHERS WHO VISIT NEW ENGLAND'S ISLANDS, I was bitten by ticks, more than once. Ten days after getting home, on a very hot day, I felt cold. I put on sweaters and heavy socks and lay down under a pile of blankets. I shivered and shook. My head pounded. More than anything, I craved sleep. I lay in bed, shivering and sweating. I finally found the strength to call my doctor, who waved away my suggestion that I might have Lyme disease.

Some days later, bruises appeared on my legs, first one and then another, and within another day, my entire body was covered in them. A friend, a nurse, saw the deep blue marks and said, "You have Lyme disease! Get to a doctor right away!" How she knew I have no idea—because they didn't look like the pictures of the bull's-eye rash I'd seen in books.

My doctor ordered blood tests. Indeed, I had Lyme. Soon my doctor was talking with specialists at the Centers for Disease Control and Prevention (CDC) in Atlanta, Georgia. I was a rare case. I had all four of the identifying factors: a verified tick bite, flulike symptoms, a positive blood test, and a bruiselike rash, known medically as *erythema migrans,* or EM. My doctor prescribed four weeks of a powerful antibiotic, doxycycline, and when the symptoms hadn't completely subsided in that time, an additional two weeks.

The antibiotics cleared the rash immediately. The fever was subdued, but not my fear. I Googled "Lyme disease" on my computer. More than a million results came up, and to my dismay, many of them were in remarkable disagreement about almost everything. There were scores of "Lyme disease associations" to consult. Which ones were useful? I had no way to tell. I read dozens of personal stories—all with the same theme. The treatment was as perplexing as its cause.

I read about Allen C. Steere, M.D., the physician who first gave the disease its name—and who later received death threats and refused to make public appearances without security guards. I read about doctors who had been hauled before their state medical boards for prescribing long-term antibiotics, risking suspension of their licenses. I was mystified. This was beginning to sound like a John le Carré novel. My journey down the information highway had left me with more questions than ever.

Some of the Web sites I visited, such as lyme-rage.info, appeared to be outlets for fury against the medical establishment and the insurance companies. I could relate to that. My health insurance had expired just two weeks before I was diagnosed. A cancer survivor, I was in the midst of applying to insurance companies when I received the Lyme diagnosis. And so, on the next application, I dutifully reported my past history—not only with cancer but now with Lyme. That application was denied. The reason stated? Lyme disease. I thought, "How could Lyme"—which I thought of then as merely an achy, flulike illness—"be worse than cancer?"

WHENEVER PEOPLE HEARD THAT I HAD LYME, THEY HAD stories to tell. That's how I learned about Lauren Lemay.

At her Gilford, New Hampshire, home, she sits on her deck looking out across the gentle view of the distant hills. For six years she has struggled with this sickness. "The day before I got sick, I ran 10 miles, played nine holes of golf, and then I painted the living room. That was my typical day," Lauren recalls.

Lauren, now 58, was an elementary school teacher, a long-distance runner, and a vegetarian for nearly 40 years. Health

ON

New

eech

time

of my

olitics

ars.

who first
d death
ut secu-
d before
antibi-
ied. This
My jour-
ith more

age.info,
establish-
that. My
ore I was
plying to
diagnosis.
d my past
me. That
disease. I
of then as
cer?"

THEY HAD
emay.
sits on her
istant hills.
.. "The day
les of golf,
ypical day,"

her, a long-
ears. Health

---

was her constant companion. "The next day, I was getting ready to go teach, and I just couldn't move," she says. "I was so tired, like nothing I ever remember in my life; I just wanted to sleep. I dragged myself to work, got through the day, and came home and slept and slept. And I was freezing. It was a hot day, and I crawled into a sleeping bag and curled up in a chair, shivering."

That was only the start. With increasing desperation, Lauren consulted 15 or 20 doctors and was diagnosed with chronic fatigue syndrome, Crohn's disease, anorexia, depression, and empty nest syndrome. When she ran out of physicians in her local area, she consulted doctors at Boston's Lahey Clinic and Beth Israel Deaconess Medical Center. When she found no relief there, she continued to seek. She visited a Chinese doctor, a psychic, a Venezuelan shaman, and a woman who conducted business out of a yurt in the middle of the woods in Western Massachusetts. "I was ready to try anything," she says.

She wasted away to 94 pounds and could hardly walk: "I was so scared. I would see it in people's faces; I'd be hanging on to my husband's arm, hanging on to the grocery cart. Me, who was always on a bike or running up a mountain. By that time, there was so much wrong with me, I felt I was dying."

LAUREN LEMAY: A FORMER LONG-DISTANCE RUNNER, SHE HAS FOUGHT LYME'S DEVASTATING EFFECTS FOR SIX YEARS. "I WAS READY TO TRY ANYTHING ... THERE WAS SO MUCH WRONG I FELT I WAS DYING."

Lauren was tested for Lyme half a dozen times. The results were negative—but Lyme blood tests are widely known for both false positives and false negatives. In New York, finally, a "Lyme literate" physician, or "LLMD," determined that she had advanced Lyme disease and put her on a doxycycline derivative. "I was on it a year and a half," she says. "The medication made me sick to my stomach, and I had to go off it sometimes. But I'm so much better now. Now I'm off the antibiotic and seeing a Vietnamese practitioner in addition to my doctor in Portsmouth. I'm not all the way there yet, but I'm back to work part-time."

LAUREN WASN'T THE ONLY LYME PATIENT I MET WHO HAS wandered helplessly through the narrow, darkened hallways of conventional and alternative medicine, seeking relief from their myriad symptoms. It turned out to be a rather common story, in fact—one that stretches back in time some 50 years.

During my research, I came across a book called *The Widening Circle*, by Polly Murray. Published in 1996, it tells the story of the early history of Lyme disease.

In 1956, Polly Murray, an artist and housewife in Essex, Connecticut, began to suffer an array of inexplicable health problems. Doctors couldn't find a cause. While she was pregnant with their second child, she and her husband, Gil, moved across the Connecticut River to Lyme, a pastoral place with views of the big river and of Long Island Sound.

PROTECT YOURSELF

1. Wear light-colored long pants and a long-sleeved shirt when walking through woods, tall grass, ground cover, or beach areas. For even better protection, tuck your pants into your socks and your shirt into your pants.
2. Consider using an EPA-approved tick repellent.
3. Check your skin (even covered areas) for ticks after an outing.
4. Promptly remove any ticks you find. Wear gloves and use a tick puller (such as the tool made by Ticked Off of Dover, NH; 800-642-2485, 603-742-0925; tickedoff.com) or fine-point precision tweezers.
5. Consult your physician immediately if you experience any of the following symptoms: bull's-eye or expanding solid rash, swollen or painful joints, swollen glands, headache, fever, chills, sore throat, stiff neck, numbness or tingling in arms or legs, abnormal vision, abnormal pulse, facial paralysis, or severe fatigue.

KIRBY C. STAFFORD: CONNECTICUT'S STATE
OMOLOGIST HAS COMMITTED 19 YEARS OF
CAREER TO TICK RESEARCH. "[LYME DISEASE]
T GOING AWAY."

A precise person, Polly kept a record of her family's com- aints. By 1964, they had four children, all suffering from shes, fevers, aching and swollen joints, and diarrhea. Visits to e doctor were frequent; relief was rare. In fact, thumbing rough the symptoms Polly recorded throughout the 1960s, u might think you were looking at the notes of a severe pochondriac—except that her tire family was suffering from ese complaints.

Eventually, doctors committed lly to a Boston psychiatric hospi- l. After two weeks of tests and ob- rvation, she came home with eeping pills and antidepressants. t she continued recording all that as happening to her. And what as happening to her didn't stop.

She discovered that other people the shore area were experiencing e same ailments. She compared otes with Judith Mensch, who ed in Old Lyme, and in October 975 they called the state health epartment to report the plethora of symptoms that were plaguing them, their families, and now their neighbors. Polly asked for an investigation. When she told her doctor what she'd done, he was furious and accused her of "stirring up trouble."

Nevertheless, on November 20, 1975, she was referred to Yale University to consult Allen Steere—a rheumatologist who had spent his first two years out of medical school working for the Epidemic Intelligence Service (EIS), an arm of the CDC. Steere showed a deep interest in her case and wanted all her notes. She also gave him the names of other people she knew who were suffering as well.

By early in the new year, Steere had recorded 39 children and 12 adults from the Lyme area who were experiencing these symptoms—all of which he connected to the bite of a tick, and which he collectively called "Lyme arthritis," a term that was later broadened to "Lyme disease."

On a national television news show, Steere explained the epidemic. Irate that their town was now on the map for unwelcome reasons, Lyme residents accosted Polly again and again. Fear spread that the town's real estate values would plummet.

From that small circle grew an epidemic of similar stories—people with elusive symptoms that could not be conclusively diagnosed. Doctors surmised that they had fibromyalgia, multiple sclerosis, amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), lupus, and sometimes Parkinson's. Yet this mystifying tick-borne illness was little known outside the growing number of Connecticut and Long Island shoreline communities where it was prevalent.

LYME WARS

Controversy over the management of chronic Lyme disease has split the medical community in two. At the national level, one side is led by the Infectious Diseases Society of America (IDSA, based in Alexandria, Virginia), a professional association of specialist physicians and researchers whose guidelines for diagnosis and treatment have been adopted by the Centers for Disease Control and Prevention. This group maintains that the symptoms of Lyme are objective and concrete and that most cases may be cured with a limited course of antibiotics (typically about three weeks). On the other side of the aisle is the International Lyme and Associated Diseases Society (ILADS, based in Bethesda, Maryland), an organization of scientists and health-care professionals who acknowledge the existence of chronic Lyme infection and who advocate for the prescription of long-term antibiotic therapy when appropriate. This group has issued its own diagnostic and treatment guidelines. Now wading into the midst of the debate is Connecticut Attorney General Richard Blumenthal, who has launched an antitrust probe of IDSA, citing some members' potential conflicts of interest that may have influenced the development of the organization's guidelines. For detailed information on the two professional groups, visit idsociety.org and ilads.org; for more on the status of the investigation, go to ct.gov/ag.

F

S

In April 19
was recorded
Agricultural E
quoted as say
certainly were
they had been
Polly's exp
Lemay's. But I
passed in the n
and drove to N

KIRBY C. STAF
entomologist,
ment Station in
ing to talk abou
of a deer tick (
I. dammini, or
up to almost h
wall. Under ma
powerful and in
tank. It is, he t
glee, "the ideal
Stafford gest
nets: "Ticks, Lyn
years. The Polly
mid-'70s. Allen S
in 1977, and the
in 1982. After th
He's telling me
Borrelia burgdorfer
terium that spir
the mouths of tic
The mustach
cise demeanor, a
case stuffed into
picture of a dedi
"At that time, th
you could be tes
Dr. Louis Magnar
Even as we ta
Stafford's office a
removing ticks r
Some 6,000 ticks
tists grind them u
chete bacterium
hundreds of thou
and even deeper i

From that small circle of shoreline communities grew an epidemic of similar stories—people with elusive symptoms that could not be conclusively diagnosed.

In April 1979, a dramatic increase in the number of ticks was recorded in Lyme and its environs. The Connecticut Agricultural Experiment Station, however, was inexplicably quoted as saying that ticks were "new to the state." They certainly were not new to Polly and her neighbors. By then, they had been plagued by ticks for more than 20 years.

Polly's experience sounded alarmingly like Lauren Lemay's. But I had to remind myself that a half century had passed in the meantime. I shook myself back into the present and drove to New Haven to see a tick specialist.

KIRBY C. STAFFORD III, PH.D., THE CONNECTICUT STATE entomologist, sits in his office at the Agricultural Experiment Station in New Haven, more than willing to talk about his favorite subject. A picture of a deer tick (*Ixodes scapularis,* also known as *I. dammini,* or the black-legged tick), blown up to almost human proportions, adorns his wall. Under magnification, the creature looks powerful and indestructible, like a prehistoric tank. It is, he tells me with almost paternal glee, "the ideal parasite."

Stafford gestures to his wall of filing cabinets: "Ticks, Lyme disease—I've been in it 19 years. The Polly Murray thing happened in the mid-'70s. Allen Steere published his first paper in 1977, and the organism itself was discovered in 1982. After that, things proceeded rapidly." He's telling me about the cause of the diease: *Borrelia burgdorferi,* the corkscrew-shaped bacterium that spirals its way into humans from the mouths of ticks.

The mustachioed Stafford has a calm, precise demeanor, and with pens and eyeglasses case stuffed into his shirt pocket, is the very picture of a dedicated scientist. He continues: "At that time, the only place in the country you could be tested for Lyme was right here. Dr. Louis Magnarelli developed the test."

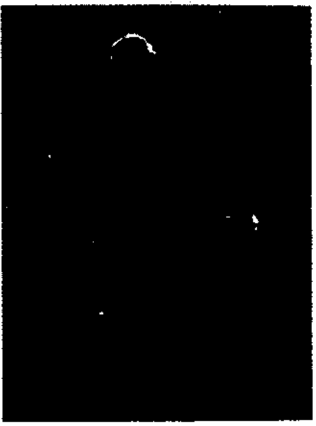
Even as we talk, researchers in a lab near Stafford's office are opening up envelopes and removing ticks mailed to them for analysis. Some 6,000 ticks arrive here each year. Scientists grind them up and test them for the spirochete bacterium that has bored its way into hundreds of thousands of Americans to date, and even deeper into their consciousness.

Stafford is the author of the *Tick Management Handbook,* a booklet that is distributed throughout southern Connecticut. (It's also available online at caes.state.ct.us.) In it, he discusses tick biology, tick-borne illnesses (Rocky Mountain spotted fever, ehrlichiosis, babesiosis, encephalitis, tularemia, Lyme disease), prevention, chemical control, and landscaping methods to reduce the *Ixodes* population—in part by managing the numbers of deer, white-footed mice, and chipmunks (all principal hosts of disease-bearing ticks) on one's property.

"It's not going away," he says confidently. He shows me the CDC's incidence map, noting how the disease has spread from those early days in Lyme—the concentrations now radiating like a dark stain all the way out into the Northeast.

MARJORIE TIETJEN: EIGHTEEN YEARS OF COPING WITH LYME HAVE TURNED HER INTO AN ACTIVIST. "MY FRUSTRATION HAS BEEN THAT WHEREVER I GO, NO ONE FOCUSES ON THE ROOT OF THE PROBLEM."

One comment I heard more than once is that Lyme doesn't kill you—but you wish it would. Its mysteries are haunting. And then there's the 'biopolitical' aspect.



Dr. Peter Rand's study of deer on Monhegan Island, Maine, concluded that they were primary Lyme tick carriers.

Indeed, 49 states in the Union have now reported cases. There are a number of places where Stafford and his researchers have been collecting ticks for many years, including Polly Murray's backyard.

"How does Lyme spread?" I ask.

He shrugs: "Migrating birds. There's no sure way to know. The movement of deer and the way people travel to tick-infested areas with their pets—all can be factors. But it's widely believed that birds played a role in a lot of this." He shows me the tick's life cycle, which involves at least four critical stages. "It's like a mechanism that needs all the parts to function," he explains.

Having thought of the tick as an indestructible machine, I suddenly think it's a miracle that any tick survives with so many bridges to cross until it reaches the final stage on the back of a moving deer. "What about reducing the number of deer?" I ask.

"We've been wrestling with that for a number of years," Stafford replies. "We've done studies, and we've found that it can help substantially. But people get kind of exercised about hunting deer."

"IMAGINE VIRTUALLY ELIMINATING Lyme in five years! I've been living in the epicenter of the Lyme world for four years already. We could be almost done by now."

In her clipped British accent, Georgina Scholl, M.D., is talking about her passion: killing deer to save people. Slender, auburn-haired, dressed in linen, she's the vice chair of the Fairfield County Municipal Deer Management Alliance, a group that provides residents with a "deer hotline" and information on hired hunters. These towns, which suffer the highest incidence of Lyme disease, are trying everything they can to contain this epidemic.

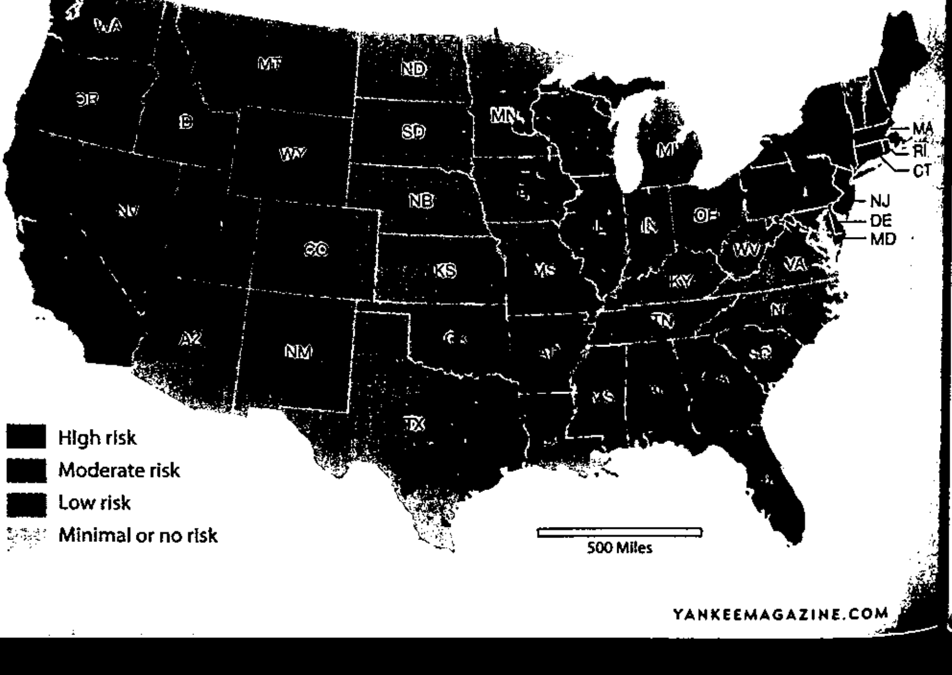
Outside the French doors of her kitchen in Redding, Georgina looks out on a wildflower meadow that slopes gently toward the woods. The turquoise waters of the family's pool ripple in the breeze. This bucolic scene, once their paradise, is now a kind of no-man's-land for her family—what she calls "no child left outside."

"We moved here to be in the country," she explains. "We built a treehouse for our sons at the edge of the field, and that of course is where the ticks are. And then we found out about Lyme. We had no idea." Georgina is a neurologist; her husband is an immunologist. "The problem is, we've got too many deer," she adds. "Why would anyone tolerate a problem that's destroying the woodlands, causing fatal car accidents, and spreading disease?"

Last summer, Georgina and her husband took a trip to Maine and stayed on Monhegan Island, where there are no ticks. "It was wonderful to be somewhere where they weren't," she notes. But it wasn't always so.

TRACKING LYME'S SPREAD

From its origin on Long Island Sound 50 years ago, this tick-borne disease has worked its way across the country. The western Great Lakes region is the next most dangerous area after the northeast coast.



DR. CHARLES RAY JONES: HERO OF THE CHRONIC LYME COMMUNITY, HE IS ALSO THE TARGET OF A MEDICAL LICENSURE HEARING. "IT'S A HIGH-RISK TRADE . . . I'M CONSIDERED THE GREAT SATAN."

ON MONHEGAN ISLAND, A LITTLE ROCK OF a place 10 miles out in the ocean off the coast of Maine, Peter Rand, M.D., and his band of fellow sleuths at the Maine Medical Center Research Institute have spent almost 20 years studying the relationships among deer, rats, and ticks, and how their population levels correlate with the spread of Lyme disease. "Oh, I'd love to write a book about all this," says Rand, a handsome man in his 70s, with a full head of white hair and a patrician bearing. From his office in South Portland, he loves to tell the story, an adventurous tale of trips to the island on the high seas, collecting ticks in the snow, and late-night sessions around a roaring fire, the team talking about the future of their research. "The beauty of the island was that it was *contained,*" Rand explains. A scientist's dream.

For part of that time, most of the 75 full-time residents of Monhegan acted as guinea pigs; the island's little general store became their makeshift clinic. "The people would come down and put their arms on the meat counter, and we'd draw blood," Rand recalls. Dogs and cats were tested, too. He sometimes felt as though he were on the set of M*A*S*H.

His team worked like that for 13 years: "We found that as the years went on, up to 13 percent of the island's residents had Lyme." The local fear was that the presence of the disease would scare away visitors, who provide Monhegan with vital revenue. And so, after furious debate, residents agreed to have all the deer killed. Between 1996 and 1999, more than 100 deer were shot and their carcasses processed (the meat was donated to food banks), effectively removing the most active tick host from that island. And now, six years later, Lyme is virtually nonexistent on Monhegan. Rand's study was a triumph in the annals of Lyme disease prevention.

ONE COMMENT I HEARD MORE THAN ONCE IS THAT LYME doesn't kill you—but you wish it would. In Brunswick, Maine, I visited Rita Losee, a little fireball of a redhead who was once a nurse and a triathlete. Bitten by a tick while hiking the Appalachian Trail, she was diagnosed quickly, but when she'd finished the recommended course of antibiotics, her symptoms returned. "There were three or four times when the pain was so awful, I was within days of killing myself," she remembers. Her doctor changed her diagnosis to chronic fatigue syndrome. At first she believed him—but then she started researching on her own. "I convinced my doctor to put me back on antibiotics," she says, "and I started to feel better again."

The mysteries of Lyme haunt her: "One of the things that really puzzles me is that so many doctors refuse to know about Lyme. I was in touch with one doctor, and he and his family all had Lyme. I called him up and he said, 'I don't want to talk about this on the phone,' and he invited me over. I felt as if I were in a Kafka novel. I've never felt anything like this, the strange energy that surrounds Lyme. I asked him about it, and he talked about the denial that exists around Lyme. And then he told me that there was a writer for *Newsday* who started investigating, and he traced the whole thing to a little island off Long Island where the United States has a biological factory, and that this Lyme bug was an escapee."

I KNEW WHAT RITA MEANT BY THE "STRANGE ENERGY" surrounding Lyme. When I visited Georgina Scholl and asked her to explain the controversy, she covered my tape recorder with her hand and whispered, "Please!" And then she said, as if in mediation, "Why do we have to have this disagreement? Let's just get rid of Lyme!" Kirby Stafford and Peter Rand both told me they wouldn't answer questions about the "biopolitical" aspect of Lyme. *What did they mean by that?* I wondered. What was there about this disease that could not be discussed?

And then I met Marjorie Tietjen, a sweet-natured woman who lives with her husband and son in a house in the woods of Killingworth, Connecticut. Marjorie, who has suffered from Lyme since 1989, calls herself a Lyme activist. I'd read

One way to stop an epidemic is to redefine it … And one way to control an outbreak is to determine which doctors can treat it and which ones cannot.

her articles on the Web and was impressed by her wealth of information. She welcomed me to her home. Like almost every other Lyme patient I'd visited, she had stacks of papers and folders piled on the dining room table.

Marjorie had her own story to tell me, but she also had a book she wanted to give me: *Lab 257: The Disturbing Story of the Government's Secret Plum Island Germ Laboratory* by Michael Christopher Carroll (HarperCollins, 2004).

Carroll discovered that Plum Island, which sits in eastern Long Island Sound, was set up after World War II with the help of Erich Traub, a German germ warfare expert. During the war, Traub had operated a lab on an island in the Baltic Sea. Islands, it was thought, were ideal for such research, as they're self-limiting. But we know now that that's an illusion. As Carroll points out: "Plum Island lies in the middle of the Atlantic flyway, the bird migration highway that runs between breeding grounds and winter homes from the Caribbean to the Florida coast, up the East Coast to the icy reaches of Greenland. In addition, deer swim back and forth between the island and the mainland."

Compiling information received through the Freedom of Information Act, Carroll details Plum Island's shadowy netherworld: virus outbreaks, biological meltdowns, infected workers, contaminated raw waste flushed into the Sound … and experimental tick colonies, bred for research on vector-borne diseases.

AS THE BIG WHITE FERRY *NEW London* pushes forward into deep water, steel-gray clouds hide the sky. The trip to Long Island takes about an hour and a half, and midway through our journey, on the port side, Plum Island appears, crowned with a water tower and edged with large, flat-roofed buildings. Off the island's shores, fishing boats and pleasure craft bob. At its tip, a picturesque granite-based lighthouse sits, like a photo on a postcard.

On the map, Plum Island lies like an arrow, one end pointing toward the Connecticut coast and other toward Long Island's North Fork. At the same time that Polly Murray and many others in that area were beginning to experience bizarre symptoms, Plum Island's germ research was up and running. Birds, stopping on Plum Island, often flew next to either Montauk (on the South Fork) or Lyme, where the rich estuaries of the terminus of the Connecticut River lured them. Initially, the highest incidences of the disease were in Lyme and surrounding towns, and at the tip of Long Island.

Lab 257 has been shut down, but other labs on the island perk along. If infected ticks did escape from this island, they've long since done the damage and nothing can stop them now; *Borrelia burgdorferi* is out and about, doing its job, making people sick.

And as it spreads, physicians and researchers continue to squabble among themselves: Some say that long-term antibiotics are the only way to treat Lyme, while the more conventional among them advocate only short doses of antibiotics—and believe that if a patient needs a longer protocol, the illness must not be Lyme. Insurance coverage is often denied.

One way to stop an epidemic is to redefine it. Recent guidelines issued by the Infectious Diseases Society of America (IDSA) have narrowed the disease's diagnostic criteria so tightly that it's hard for any chronically ill Lyme patient to fit the profile—leaving thousands of people robbed of an answer.

And one way to control an outbreak is to determine which doctors can treat it and which ones cannot. According to the Lyme Disease Association, since the early 1990s more than 30 Lyme specialist physicians in 10 states have been brought before state medical boards under charges of overdiagnosing Lyme and overtreating with antibiotics. This, of course, is a chilling development for doctors who want to treat Lyme patients.

PROTECT YOUR PET

1. Brush pets after outings and inspect them for ticks, especially if they've been running in woods, brush, or tall grass. Keep the grass mowed in areas where your pets play. If you use any type of pesticide in your yard, make sure it's approved for use around pets.
2. Promptly remove any ticks you find. Wear gloves and use a tick puller (such as the tool made by Ticked Off of Dover, NH; 800-642-2485, 603-742-0925; tickedoff.com) or fine-point precision tweezers. Grasp the tick as close to the skin as possible, pull it straight out (don't crush it or puncture it), and dispose of it in a vial of rubbing alcohol. Swab the bite and your tool with antiseptic.
3. Wash your pet's bedding and vacuum your home regularly. If you use an indoor parasiticide, make sure it's approved for use around pets.
4. Talk to your veterinarian about the benefits and risks of the canine Lyme vaccine and ask whether it's appropriate for your dog. (A vaccine for cats is not yet available.) Ask whether a topical tick repellent or parasiticide, whether prescription or over-the-counter, is also appropriate for your pet.
5. Consult your veterinarian immediately if you see any of the following signs in your pet: swollen joints, lameness, lethargy, fever, or low appetite. Antibiotic therapy is highly successful in animals, but if left untreated, Lyme disease may cause arthritis, heart disorders, neurological impairment (resulting in confusion or aggression), or severe (and potentially fatal) kidney disease.

PHOTOGRAPH BY ERIC ISSELEE/ISTOCKPHOTO

AMY TAN'S JOURNEY

Lyme disease—also known as neuroborreliosis when it invades the central nervous system—does not discriminate among potential victims. Best-selling literary novelist Amy Tan has suffered from Lyme since 1999. Her disease baffled her doctors at first. She experienced the usual flulike symptoms, rash, and then muscle pain, but as the disease escalated, she began to hallucinate. "My memory was held together with friable threads ..." she writes on her Web site. "I easily became lost in stores and would panic, certain I was losing my mind ... Eventually, I could no longer leave my house alone ... My muscles were stiff, my knees and hips ached. And I was almost too tired to care anymore." At last she was diagnosed with Lyme and has become an activist in the fight to boost awareness of the disease. Amy Tan's 2003 essay collection, "The Opposite of Fate," includes an account of her experience. For more on Amy's story and a list of links and resources, visit: amytan.net/LymeDisease.aspx

CHARLES RAY JONES, M.D., IS A 78-year-old pediatrician whose New Haven practice has embraced 10,000 children with Lyme since 1968. "I didn't know I was treating Lyme patients at the time. There was no such thing," Jones says. In fact, he's not only the world's foremost pediatric chronic Lyme disease specialist, he's virtually the only one.

I've come to see him on a rainy Sunday afternoon, the only day of the week he doesn't see patients. A humble man, Jones lives in an apartment in an unremarkable high-rise. His commute to his office is a flight of stairs.

His patients come from all over the country to his office, just down the street from Yale's School of Medicine. In addition to seeing patients all day long, for the past year he's been driving north on a regular basis to a Hartford hearing room, trundling a wheeled suitcase filled with papers relating to the case against him, which may rob him of his license to practice.

He greets me in the courtly manner of his generation, almost bowing. In placid tones, he explains his life with Lyme. In the 1960s, he was a staff physician at Memorial Sloan-Kettering Cancer Center in New York. During that time, he and his wife began to look to the Connecticut countryside as a better place to raise their children. In 1968, they moved to Hamden, then a sleepy hamlet beside the Connecticut River, and he set up his practice.

"I started seeing children in clusters with what we thought was juvenile rheumatoid arthritis," he says. "This was very rare. But it wasn't really JRA. It didn't fit the whole picture. The clusters were not just in Lyme; they were all around. And there were many of them. Polly [Murray] was instrumental because she demanded they do something about this."

Along with Allen Steere and Eugene Shapiro, M.D., who now sits on the opposite side of the hearing room, Jones worked to solve the puzzle of this peculiar, crippling ailment. "Sure, we were colleagues at first," he notes. "We were all trying to figure it out. You could say we were mired in a lack of understanding." For Jones, this search for knowledge transformed into his specialty. He became an LLMD, Lyme literate by evolution.

"At what point did all this become contentious?" I ask.

"I was never part of that," he says. "I heard things, but I was busy. I just figured that was their problem."

Now it's his problem, too. Jones has been charged with diagnosing two children in Nevada with Lyme disease before examining them, and with prescribing antibiotics for them over the phone. Shapiro, his former colleague, a professor of pediatrics and epidemiology at Yale's medical school, not only brought the charges against Jones but also helped write the guidelines that have narrowed the disease's diagnostic and treatment guidelines. The *Hartford Courant* once quoted Shapiro as saying that he had had calls from physicians in Connecticut "begging me to see their patients so they don't have to see Dr. Jones."

On the day I visit, Jones sits at his desk in a big leather swivel chair. On the desk are neat stacks of patient files. For the hearing, which he calls variously a "conspiracy," a "witch hunt," and an "inquisition," his accusers have subpoenaed many of his charts. "I'm considered the great Satan," he says with a gentle smile, "which always amuses me."

"This is not a malpractice suit," he notes. "If the charges were serious, it would be malpractice." He goes so far as to label the charges "trivial."

In his office suite are five rooms filled with patient files: 10,000 children, all the way back to the beginning. "Seventy-five percent of them are cured," he claims. For his legal defense fund, almost a million dollars has been raised by his patients' parents and, in some cases, by his patients themselves. "This little boy," he says, pointing to a photo of a cherub-faced youngster, "had a lemonade stand this summer, and he raised $33. Another little boy, 6 years old, came in with 21 cents in a paper cup."

Hundreds of parents have crowded the Hartford hearing room in support of this aging doctor, a widower of 12 years, who in any other life would be retired. "A lot of people who dealt in Lyme are no longer doing it," he says. "It's a high-risk trade. But I'm less encumbered."

Opponents debate Jones's figures, maintaining that many of these children don't have Lyme disease. If they succeed in wresting his license from him, the Lyme community will have lost perhaps the only physician left who's willing to treat these children long-term—some of whom, he says, would end up in institutions without proper treatment.

Clearly, the new diagnostic and treatment guidelines and the reduction in the number of physicians willing to see chronic Lyme patients will have a huge impact on the disease's future—and the lives of the people suffering its ravages.

I REALIZED IN TALKING WITH THESE people that my own Lyme disease is ongoing. At the time I was diagnosed, not only was I so unfamiliar with the disease that I didn't recognize the symptoms, but I was also confused by the massive amount of contradictory information available. And I was scared of what it all might end up costing. I'd already spent $731 out of pocket on tests and treatments. So I've ignored many of the painful problems I've experienced since my visit to that island paradise five years ago. Today my health hangs in the balance of a government and a medical system apparently unwilling not only to care for their constituents and patients but perhaps to take responsibility for an epidemic as well—a scourge that I am convinced can be traced to a scruffy little island at the eastern end of Long Island Sound.

Ferries loaded with cars and passengers pass it up to 30 times a day. Fishing boats pull catch just off its shores, and the big, bright lens at the top of the old lighthouse sweeps the water, night after night, year after year, warning passing ships away from its rocky edges.

RESOURCES

American Lyme Disease Foundation, Lyme, CT. aldf.com

Centers for Disease Control and Prevention, Atlanta, GA. cdc.gov/ncidod/dvbid/lyme/index.htm

Connecticut Agricultural Experiment Station, New Haven, CT. 877-855-2237, 203-974-8500; caes.state.ct.us (Tick Management Handbook)

Lyme Disease Association, Jackson, NJ. lymediseaseassociation.org/Doctor_Referrals.html

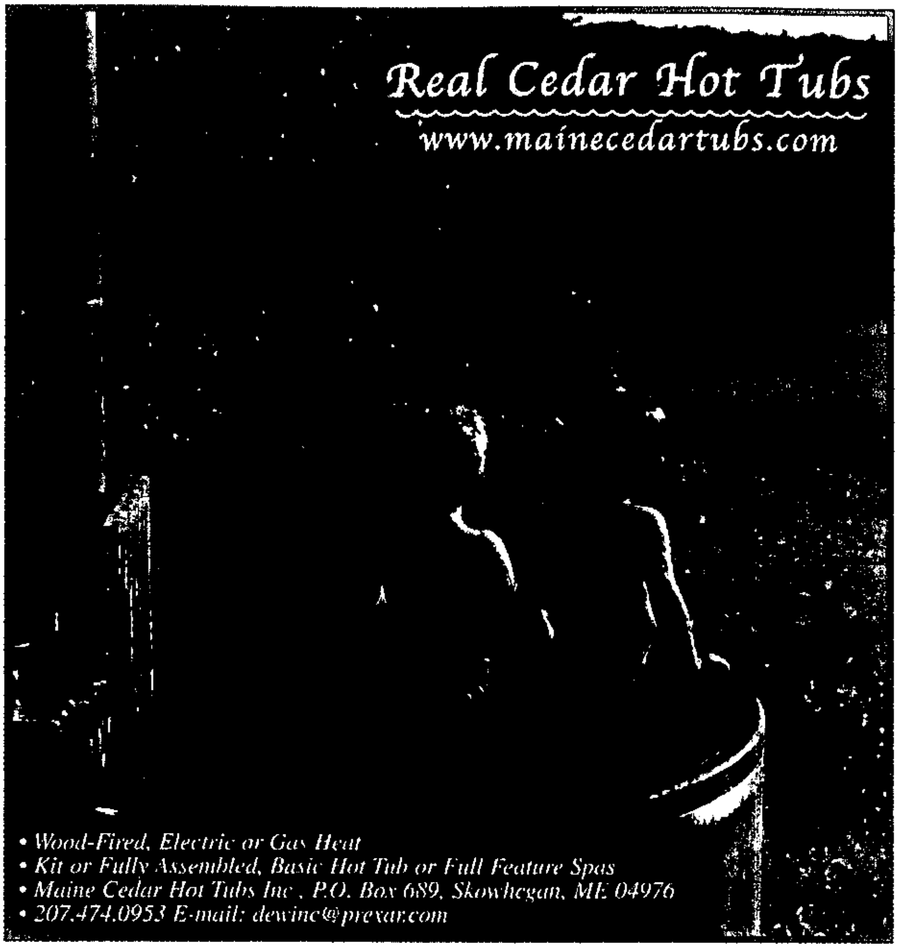
Lyme Disease Foundation, Tolland, CT. lyme.org

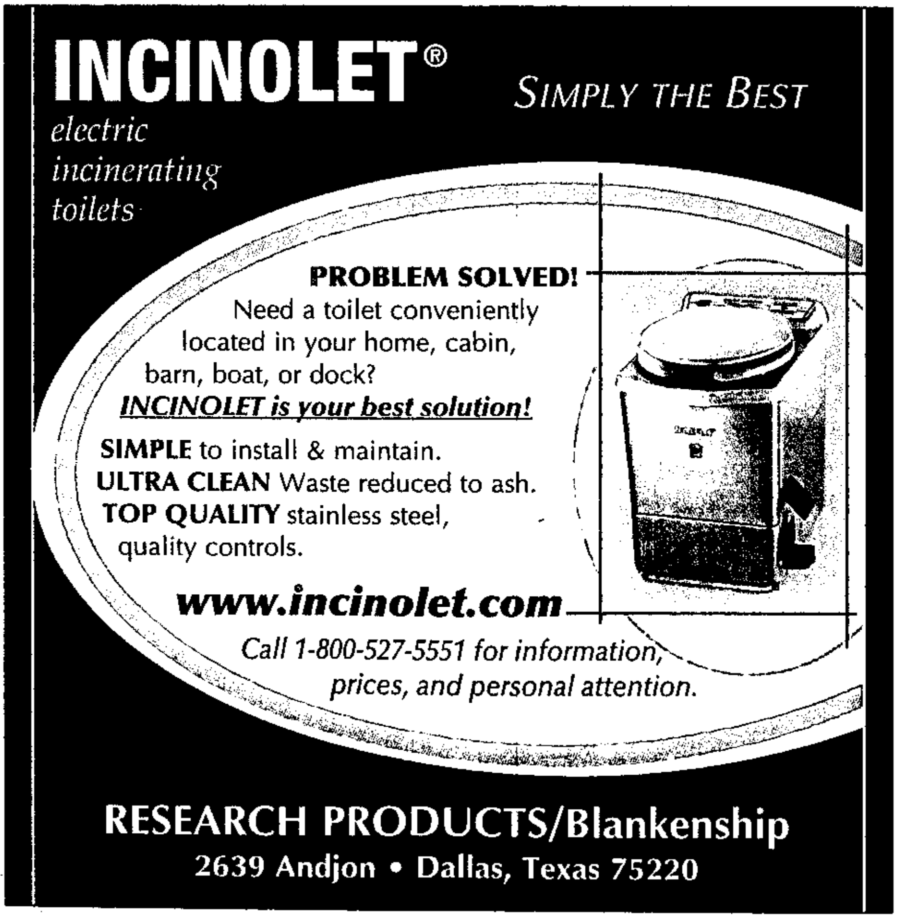
Time for Lyme Inc., Greenwich, CT. timeforlyme.org

University of Rhode Island Tick Encounter Resource Center, Kingston, RI. tickencounter.org

For information on landscaping for tick control, plus links to more resources and research news, visit:

YANKEEMAGAZINE.COM





File HB 1324
David Hunter

Testimony before the House Health & Human Services Committee

Good ~~Morning~~ AFTERNOON. My name is David Hunter. I have been involved with Lyme disease as a Lyme patient advocate for the past nine years. Currently I am facilitator for the Greater Manchester Lyme Disease Support Group and Co-Chairman of the Bedford Lyme Disease Council. I have given numerous Lyme lectures to various groups across southern New Hampshire including UNH Manchester. Lyme disease was first discovered in Old Lyme, CT back in the mid-seventies. Amazingly, some thirty plus years later 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 universal understanding and 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 stage, Lyme can become a highly debilitating illness. It is at 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 being brought up on charges just for treating Lyme patients with long-term antibiotics. We've witnessed medical boards in other states taking action against doctors for prescribing long-term antibiotic treatment for Lyme. We want to guard against this

File HB1326

happening in New Hampshire. Both of Connecticut's legislative bodies unanimously voted for a similar bill and Connecticut Governor Jody Rell signed it into 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 treat based on their medical training and clinical judgment.

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 in the vast majority of cases the infection cannot persist after four weeks of antibiotics. If properly diagnosed and properly treated in its early stage, it generally 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 as if 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

File HB 1326

treatment. Yet the IDSA strongly conveys the idea 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.

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? Hardly. It is because of their authority, status and the aggressive campaign they have waged to discredit ILADS and the ILADS guidelines. The fact is that the IDSA guidelines are so narrow and so extreme that the Attorney General of CT was compelled to launch an antitrust investigation regarding the IDSA guideline development process and found that the panel determining the IDSA Lyme Guidelines was biased with extensive conflicts of interest. In settlement of this agreement, the IDSA agreed to convene a new panel to review the current guidelines. On July 30th 2009, presenters from both sides made their arguments. ILADS submitted more than 1300 pages of peer-reviewed research in support of their analysis. There is substantial and compelling evidence opposing the guideline recommendations which the 2006 IDSA Guideline panel ignored or misinterpreted. 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.

New Hampshire ranks first in the nation 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

File HB1326

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 so more doctors will feel comfortable doing what they believe is right by their patients, using their best clinical judgment, without fear of disciplinary action. Now, I would like to ask that every NH resident in the gallery 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.

Complete Document

Can Be Viewed

In Bill Folder

Files Dr. Don McNeel HB 1336

The International Lyme and Associated Diseases Society

Evidence-based guidelines for the management of Lyme disease

Expert Rev. Anti-infect. Ther. 2(1), Suppl. (2004)

Expert Review of
Anti-infective Therapy

The ILADS Working Group
ILADS, P.O. Box 341461
Bethesda, MD 20827-1461, USA
www.ILADS.org

KEYWORDS:
antibiotics, *Babesia*, *Bartonella*, *Borrelia burgdorferi*, *Ehrlichia*, guidelines, Lyme disease, tickborne diseases

ISSN 1478-7210

The ILADS Working Group

Daniel Cameron, MD, MPH	Internal Medicine and Epidemiology, Mt. Kisco, New York
Andrea Gaito, MD	Rheumatology, Basking Ridge, New Jersey
Nick Harris, PhD	Immunology, Palo Alto, California
Gregory Bach, DO	Family and Integrative Medicine, Colmar, Pennsylvania
Sabra Bellovin, MD	Family Practice, Portsmouth, Virginia
Kenneth Bock, MD	Family Practice, Rhinebeck, New York
Steven Bock, MD	Family Practice Rhinebeck, New York
Joseph Burrascano, MD	Internal Medicine East Hampton, New York
Constance Dickey, RN	Registered Nurse Hampden, Maine
Richard Horowitz, MD	Internal Medicine Hyde Park, New York
Steven Phillips, MD	Internal Medicine Ridgefield, Connecticut
Laurence Meer-Scherrer, MD	Internal Medicine Flamatt, Switzerland
Bernard Raxlen, MD	Psychiatry Greenwich, Connecticut
Virginia Sherr, MD	Psychiatry Holland, Pennsylvania
Harold Smith, MD	Emergency Medicine Danville, Pennsylvania
Pat Smith	President, Lyme Disease Association, Inc. Jackson, New Jersey
Raphael Stricker, MD	Hematology and Immunotherapy San Francisco, California

ILADS Treatment Guidelines Overview

These treatment guidelines are intended to assist physicians and other health care providers in clinical decision-making by describing a range of generally acceptable approaches for the diagnosis and treatment of tick-borne diseases. The approach to pursue in a particular situation should be determined through the exercise of sound clinical judgment by a physician in conjunction with informed consent by a patient.

Views on what constitutes appropriate patient treatment change rapidly, and some approaches may be controversial. Health care professionals are encouraged to inform patients of all reasonable treatment options that are appropriate for their care and the potential risks arising therefrom.

The ILADS guidelines are not intended to provide medical advice to patients, who should consult with their personal physician for diagnosis or treatment. The guidelines were originally published in February 2004. Since knowledge is constantly evolving, the guidelines may be considered current only as of the original publication date.

Summary & disclaimer

These guidelines represent an evidence-based review of Lyme and associated tickborne diseases by the International Lyme and Associated Diseases Society (ILADS). Although the guidelines present evidence-based approaches to the diagnosis and treatment of Lyme and associated tickborne diseases, they were not intended to be a standard of medical care. Physicians must use their own judgment based on a thorough review of all available clinical information and the Lyme disease literature to decide on the best course of treatment for an individual patient.

Acknowledgements

ILADS would like to thank the Turn the Corner Foundation, New York, NY, for financial support of formulation of the guidelines; Medallion Media, Novato, CA, for editorial support of development of the guidelines; and the Lyme Disease Association, Inc., Jackson, NJ, for financial support of publication of the guidelines.

Table of contents

I Introduction to guidelines

1. International Lyme and Associated Diseases Society
2. Chronic Lyme disease: a growing epidemic
3. The need for new guidelines
4. A problem of definitions
5. Competency and training
6. Role of primary care
7. Highlights of guidelines

II New presentations

8. Symptomatic presentation
9. Symptoms of Lyme disease
10. Increasing evidence of persistent infection
11. Disappointing results of symptomatic treatment
12. Severity of chronic Lyme disease

III Diagnostic concerns

13. Atypical early presentations
14. Chronic Lyme disease presentations
15. The limitations of physical findings
16. Sensitivity limitations of testing
17. Seronegative Lyme disease
18. Importance of differential diagnosis
19. Clinical judgment
20. Testing for coinfection

IV Treatment considerations

21. Prompt use of an antibiotic
22. Choosing an antibiotic
23. Oral antibiotic options
24. Intravenous option
25. Intramuscular option
26. Combination antibiotic treatment
27. Sequential treatment
28. Dosage
29. Duration of therapy
30. Empiric treatment
31. Persistent Lyme disease
32. Recurrent Lyme disease
33. Refractory Lyme disease
34. Treatment failure
35. Symptomatic treatment
36. Fibromyalgia
37. Decision to stop antibiotics
38. Alternative antibiotics
39. Therapy for coinfection

V Research needs

40. Ongoing development of guidelines
41. Validation of guidelines
42. Comparative studies

VI Periodic review of guidelines

43. Grading system for evidence-based guidelines
44. Table 1: Comparison of key IDSA and ILADS guidelines
45. Criteria for evidence-based guidelines

Commissioning Editor
Laura Savill

Production Editor
Karen Blatchford

Drug Profile Editor
Vivien Griffiths

Publisher
David Hughes

Supplement proposals:
Genevieve Eastwood
Special Projects Editor
Future Drugs Ltd, Unitec House,
3rd Floor, 2 Albert Place,
Finchley Central,
London N3 1QB, UK
Fax: +44 (0)20 8343 2313
g.eastwood@future-drugs.com

Reprint purchase enquiries:
reprints@future-drugs.com

General enquiries:
info@future-drugs.com

Expert Review of
Anti-infective Therapy

www.future-drugs.com

Aims and scope

Expert Review of Anti-infective Therapy provides a centralized resource of commentary and debate to inform clinical and economic decision-making in the treatment of infectious diseases. Members of the International Editorial Advisory Panel identify the most important and topical review themes and the corresponding experts most appropriate to provide their opinion and perspective. All articles are subject to rigorous peer-review.

The Journal concentrates on a structured program of authoritative review articles, addressing:

- Therapeutic overviews of specific therapeutic areas, highlighting optimal therapy
- Performance and benefits of newly-approved anti-infective therapeutic agents
- Prospects for new therapies
- Psychosocial aspects
- Epidemiological studies and trends
- New diagnostic approaches, screening and patient stratification
- Pharmacoeconomics and outcomes

Editorial policy: Articles published in *Expert Review of Anti-infective Therapy* are commissioned by the Editor in collaboration with the Editorial Advisory Panel. Authors who wish to contribute should contact the Commissioning Editor with an outline proposal in the first instance. Guidelines are available on request or at our website.

Copyright: Conditions of sale – *Expert Review of Anti-infective Therapy* may be circulated only to those members of staff who are employed at the site at which the subscription is taken out. Readers are reminded that, under internationally agreed copyright legislation, photocopying of copyright materials is prohibited other than on a limited basis for personal use. This means that making copies of any article published in *Expert Review of Anti-infective Therapy* is a breach of the law and can be prosecuted. Whilst every effort is made by the publishers and advisory board to ensure that no inaccurate or misleading data, opinions or statements appear in this journal, they wish to make it clear that the data and opinions appearing herein are the responsibility of the contributor concerned. Accordingly, the publishers, advisory board, editors and their respective employees, officers and agents accept no liability whatsoever for the consequences of any inaccurate or misleading data, opinions or statements. Approved product information should always be reviewed prior to prescribing.

Contributions to *Expert Review of Anti-infective Therapy:* We welcome suggestions or recommendations for Guest Editorials, Meeting Reports or Reviews for publication in *Expert Review of Anti-infective Therapy*. In the first instance, please contact the Editor, Laura Savill, with a brief outline of the proposed contribution.

Please direct the proposal to:
Laura Savill, Commissioning Editor,
Future Drugs Ltd, Unitec House, 3rd Floor, 2 Albert Place
Finchley Central, London N3 1QB, UK
Tel.: +44 (0)20 8349 2033; Fax: +44 (0)20 8343 2313
l.savill@future-drugs.com

Dr. Young HB1325
File

I am talking to you today because I believe the medical system has failed.
I am a member of that medical community.
I have practiced as a primary care physician here in NH for the past 29 years.

As part of my professional work, I am on the board of Northeast Healthcare Quality Foundation, the Medicare watchdog group for Maine, NH, and Vt. As president of the board for the past 3 years, I am aware that Medicare has ranked NH quality as number 1, number 2, and number 1, *in the nation*, over the last three reporting periods (2005,2002, 2001). We get good medical care here in NH!

In view of the high quality of health care in NH, I want to contrast my own experience.

My daughter went blind –briefly-- after an appendectomy in 1997. Her blindness only lasted 15 minutes, but it reoccurred. Then she had unconscious episodes. Over the next two years, she went from honors English in High School to being unable to comprehend a newspaper article. She would frequently sleep for 20-22 hours per day, or get zero sleep for 3 days. Her symptoms were bizarre, and after two years, despite my being a physician, despite using a large group of specialists whom I knew and respected, no one could explain her problem. We had found no treatments that worked. It was a scary time.

In May of 2000, in our desperation, we decided to treat for possible lyme disease. She did not meet national CDC guidelines for that diagnosis., but she started antibiotics, and her deterioration stopped. We were ecstatic. After *16 months* of antibiotics, she was able to start college. She was still disabled and took medical withdrawals 4 semesters, but her college status allowed her to remain on our health insurance, (This was prior to Michelle's Law.) After 3 ½ years of antibiotics, her tests turned positive according to national CDC guidelines. Since then, with a total of *9 ½ years* of antibiotics, she has graduated from college and finished a master's degree.

As a physician, *I* think that issues concerning the duration of antibiotic treatment should be between a patient and his/her physician, consistent with risks and benefits, and defined by medical research.
Unfortunately, treatment of lyme disease is now a political problem, not just a medical one, due to two conflicting guidelines about the treatment of lyme disease.

You are being asked to take sides.

One side—starts with the Center for Disease Control—our federal communicable disease agency. A very smart group of people. When you go online to the CDC site and click on treatment guidelines, they give a 15 second disclaimer saying they do not endorse any organization or guidelines. The link then automatically sends you to the site of the Infectious Disease Society of America, IDSA. I guess the CDC does use IDSA guidelines for diagnosis and treatment of lyme disease.

Opposed to the Infectious Disease Society of America—is the International Lyme and Associated Disease Society (ILADS)—an organization of infectious disease specialists, PhDs in research, and primary care physicians primarily in high Lyme disease areas. A very smart group of people. These are people who literally devote their professional lives to Lyme disease.

These two groups have different guidelines.

A primary reason that smart people disagree about treatment of Lyme disease is because they disagree about how to decide who is infected and who is cured. Lyme bacteria are not like normal germs. You can't see them (except in research labs, not medical labs). They survive for extended periods in the human body by hiding, and if they can hide from the immune system, they can hide from our tests. The Borellia germ is actually seen under the microscope in less than 1% of people treated for lyme disease. Without being able to see the germ, it is difficult to prove who has the infection. It is also very difficult to prove when the infection is gone. This is the elephant in the room. IDSA and ILADS do not quite agree whom to include in lyme studies, and they use different definitions of a cure. They therefore get different results.

((It turns out that IDSA studies did not include people like my daughter. IDSA defined lyme disease differently. They admit that they did not study people like my daughter. In fact, IDSA and even the CDC are not convinced that chronic neurologic lyme disease even exists. The National Institute of Health believes it does . My daughter does. I do!))

In fact, I see patients with lyme disease in my office *many* times per month. Of those, I *currently* see *three* patients who are disabled, with bizarre symptoms like my daughter. All of them test positive for lyme disease. In deciding about their medical treatment, I specifically look for medical literature that studies people with their clinical presentation. It turns out that the literature is there, but it is not available through the IDSA site.

I can give you a site that lists 180 articles from US and international sources that support the use of longterm antibiotics in these cases. It turns out, this site is not part of IDSA or part of ILADS. This site was done by the research dean at Plymouth State University, Dr. Scott Mantie.

These 180 articles say that short course treatment (arguably 6 weeks of antibiotics) have a good probability of curing lyme disease **so long as two criteria are met**: *antibiotics are started within months of the tick inoculation, and steroids that suppress the immune system were not used prior to starting those antibiotics.* (Both occurred in the case of my daughter.) 180 articles. Some are from the New England Journal of Medicine and some are translated from Danish. The wonders of the internet!

I am not entirely sure why 180 articles are not meaningful to IDSA, but *I* find those articles helpful. I conclude from those articles that IDSA guidelines work for a majority of lyme patients, because most patients are treated quickly enough and without prior exposure to steroids. These articles also tell me that the IDSA guidelines do not work for everybody. With difficulty proving whether the germs are gone—or not—after antibiotic treatment, I am not sure if the IDSA failure rate is 3% or 15% or 30%. Every single infectious disease has a treatment failure rate. I just don't understand how IDSA can ignore those people on the wrong end of the odds.

Many of the people testifying before you today will clearly say that IDSA guidelines have failed them, that their symptoms continued despite short course antibiotics. I'm not going to suggest to those people that their disease should have gone away—they know they are still living with an illness. I am not going to suggest that their positive lyme tests are coincidental, and in fact, something else must be going on. That has been said to my family.
I know that you will hear testimony from smart physicians who argue that IDSA criteria work for a large majority. They are perhaps right. But *my* testimony is that the IDSA failure rate is unacceptable, at least for my family, and my patients. NH now has the highest rate of lyme disease per capita of all 50 states. This means that IDSA guidelines are a failure for a small percentage of a huge number. My office, and my family, is filled with statistical outliers, people on the wrong end of the odds.

One brief story. During the dark days of 2001, I insisted that our daughter be reevaluated by a neurologist. I was concerned about seizures. I took her to the seizure specialist at Dartmouth, whom I had known for years. He said that she did not have seizures. He also felt she did not have lyme disease since her blood test for lyme was negative by CDC criteria. He also said that chronic neurologic Lyme disease did not exist. As a professional courtesy, he said 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 the head of the infectious disease department at a Boston major medical center.

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 just based upon national IDSA guidelines.

I bring this up to dramatize the conflict within the medical community over the diagnosis and treatment of lyme disease.

Coincidentally, my daughter's blood test turned positive the following year.

I hope that the medical testimony you hear does not ignore patients like my daughter or like many of the other people before you today. You will not find people here today a simple lyme rash, who were cured in ten days on antibiotics. You will not find the people with lyme arthritis who were diagnosed quickly and were cured by a 6 week course of antibiotics. The people before you today have a severe and disabling and heart-breaking chronic disease that requires prolonged treatment.

The State of Conn. was faced with the same question with which you are faced. Connecticut certainly knows Lyme Disease.
They passed a bill *protecting* physicians who treat patients with Lyme Disease using long term antibiotics. It protected *their patients' right to decide*, with the help of their doctor.

I ask you to do the same. Thank you.

Susan M. Saviteer, M.D., M.P.H.

Infectious Diseases - Board Certified
Hospital Epidemiology

Concord Hospital
250 Pleasant Street
Concord, New Hampshire
(603) 226-3225
(603) 226-1726
Fax (603) 228-7357

File HB 1320 1*

(i)

Dr. Susan Saviteer

Bd certified in IM + ID.
Practice in Concord NH x 21 years. — referral-based practice ~~community-based~~
retired in '07 & I ~~therefore~~ have NO personal stake in the outcome of this legislation. nothing at stake

med school in CT - early years of clin dx — resid MCV
4 yr ID fellowship in UNC Chapel Hill
PH / Epid degree - same institution - invol in the crit. review of med. publications

REP. NH MED Soc + IDSA → IN OPP TO THE BILL
~~Because I have nothing at stake [illegible] of a practice~~.

I hope that I can bring a ✓ FAIR assessment ✓ OBJECTIVE " of the mgmt of Lyme Dz
+ the advisability of long term Rx

the preeminent
IDSA - official assoc of ID doctors
9000 members ID specialists
GUIDELINES - all trained in ID DIS
anfoo endocarditis
IDSA position paper -
clinical practice guidelines
IDSA
11/06
14 internationally-recog physicians + scholars
10 prominent research centers MGH
Boston Med Center

What you hear in the news is the push to move to → EVIDENCE BASED MEDICINE
what is that -
critical rev of lit
by recog physicians & scientists
Practices scientific data reviewed
the best objective data is reviewed and
|
med is practiced accordingly

Each rec is rated according to the strength of the evidence
the decisiveness of the scientific study
(design / outcome)

~~GUIDELINES FOR mgmt OF ID~~ from IDSA GUIDELINES
EACH REC IS RATED ACCORDING TO THE STRENGTH
OF THE EVIDENCE + THE DECISIVENESS of the
SCIENTIFIC DATA

*

Susan M. Saviteer, M.D., M.P.H.

Infectious Diseases - Board Certified
Hospital Epidemiology

Concord Hospital
250 Pleasant Street
Concord, New Hampshire
(603) 226-3225
(603) 226-1726
Fax (603) 228-7357

The diagnosis/treatment of LD can be confusing/complicated to
physicians who do not manage/study patients on a regular basis
+
to the public

Yet the clinical manifestations of LD are well-characterized
and the Rx guidelines for these are well-described.

Lyme Dz in all its stages is readily treatable with short course of abx.

The IDSA Guidelines provide a sound scientific framework for
the mgmt of pts c̄ LD.

Lyme + Borrelia +

Early Lyme Dz is often char by skin lesions
and if untreated a small # (10-15%) go on to
develop heart problems + nervous system problems

untreated, the course may progress to late Lyme dz
characterized by arthritis, nervous system disorders

Dx
- hx - Lyme exposure + plausibility of exposure
- review of sx.
- complete pex -
- lab - std 2 tier blood test FDA + IDSA ELISA / WB. 2 Tier
- spinal fluid is studied in cert

All of above contribute - sx/labs alone dx EVID BASED

Many lab tests are marketed for the dx of Lyme dz - . .
Based on studies of test validity the FDA has not approved these tests
I believe this is evidence-based medicine

Susan M. Saviteer, M.D., M.P.H.

Infectious Diseases - Board Certified
Hospital Epidemiology

Concord Hospital
250 Pleasant Street
Concord, New Hampshire
(603) 226-3225
(603) 226-1726
Fax (603) 228-7357

*

LD is managed with oral abx for durations <28 days in all but a few scenarios.

Nervous System involvement warrants a 2-4 week abx treatment - IVs
Heart Dz - IV / PO
Recurrent arthritis - objective swelling/warmth/tenderness of joint - that recurs p̄ initial course → IV/PO

IDSA Guidelines - Category A/B (strongly / mod strongly) rec that Rx not exceed the 2-4 wk rec. course for LD.

● In No instance should Rx extend beyond 2 courses.

Excessive doses of abx
mult repeated courses of abx.
pulsed dosing
} not rec in any clinical setting

→ EVIDENCE BASED MED

*

Susan M. Saviteer, M.D., M.P.H.

Infectious Diseases - Board Certified
Hospital Epidemiology

Concord Hospital
250 Pleasant Street
Concord, New Hampshire
(603) 226-3225
(603) 226-1726
Fax (603) 228-7357

controversy -
chronic lyme exist?

After acute illness with Borrelia with appro. abx therapy
it can be expected that a some minority of pts will have
Sx for wks - mos.

As with many illnesses → slowly resolve c̄ time
patience.

There are patients who have been labeled classified -

Syndrome { post. lyme dz syndrome.
post - treatment chronic lyme
chronic LD }

working def
ⓐ well doc dx
ⓑ subjective Sx
MS pain
fatigue
cognitive defects { memory
word findin
sequencin
ⓒ no findings on exam.

Sx begin within 6 mos Rx.
last > 6 mos

③ well done studies have addressed these patients
prospective, randomized, double blind, placebo-controlled.

All pts had hx of definitive dx, had rec'd abx, had cont Sx

Randomized to receive additional IV + PO drug OR placebo
At 3 + 6 mos - No diff between groups.

No objective Evidence that pts with dx + rx'd LD
who have a chronic symptoms RESPOND to further abx.

THIS IS EVID - BASED MEDICINE

Susan M. Saviteer, M.D., M.P.H.

Infectious Diseases - Board Certified
Hospital Epidemiology

Concord Hospital
250 Pleasant Street
Concord, New Hampshire
(603) 226-3225
(603) 226-1726
Fax (603) 228-7357

As physicians, we must be very careful

NOT to give pts a dx of LD unless they meet clinical criteria.

- pts with M.S pain
  fatigue
  memory deficits

~~pts with~~

} these are common sx in our society (>10%)

↓

they should not be given a dx of LD without thorough evaluation.

THIS IS EVID-BASED MED

ST
sweats
swollen glands.
stiff neck
abd pain
back pain
n/a
dizziness

Susan M. Saviteer, M.D., M.P.H.

Infectious Diseases - Board Certified
Hospital Epidemiology

Concord Hospital
250 Pleasant Street
Concord, New Hampshire
(603) 226-3225
(603) 226-1726
Fax (603) 228-7357

10

1326
HB ~~[illegible]~~ addresses long term abx therapy for Lyme Dx
Such therapy carries sig risk
Risk of long term abx -

- infection - abx kills off certain bacteria
while others proliferate
perfect recipe for emergence of super-bugs

Rx →
IMBALANCE eg - Clostridia difficile
a bact that causes colitis and is
life - threatening

→ problems rel to the abx
CFTX - most efficacious drug for Lyme mgmt
- gallstones sludge
gall bladder surgery

→ problems related to the del system
If IV → infex at the IV site
→ bacteria in the blood
a risk to the heart valves
→ pulm. embolism
→ thrombosis (clotting) of the vein

long term abx therapy not only is not rec for the
mgmt of Lyme but it is asso c̄ sig risks
some life threatening

Susan M. Saviteer, M.D., M.P.H.

Infectious Diseases - Board Certified
Hospital Epidemiology

Concord Hospital
250 Pleasant Street
Concord, New Hampshire
(603) 226-3225
(603) 226-1726
Fax (603) 228-7357

one additional thought -

is chronic Borrelia a logical / plausible condition?

Scientists have shown

- no abx Ⓡ in this class of bacteria
- no evid that the bacteria can escape the immune system.
  not in immunocomp pts
  not an intracellular pathogen.
- other bacteria in this category
  Syphilis do NOT cause chronic infxn ~~[illegible]~~,
  if Rx'd appropriately

So ~~SCIENTISTS~~

IT'S JUST NOT SCIENTIFICALLY SOUND
TO CONJECTURE THAT BORRELIA
CAUSES ~~[illegible]~~ DEEP-SEATED
CHRONIC
INFXNS

Susan M. Saviteer, M.D., M.P.H.

Infectious Diseases - Board Certified
Hospital Epidemiology

Concord Hospital
250 Pleasant Street
Concord, New Hampshire
(603) 226-3225
(603) 226-1726
Fax (603) 228-7357

- IT IS IMPERATIVE THAT WHENEVER POSSIBLE WE STRIVE TO KEEP THE SCIENCE IN MEDICINE.
  ~~TO STOP~~ HB 1326 should not be the place where specific medical treatment is sanctioned.
- IDSA DOES NOT SUPPORT LONG-TERM ABX THERAPY FOR L.D.
  Neither does Am Acad Neurology
  + numerous scientific experts
- TO PRESCRIBE LONG-TERM ABX IS TO PLACE PATIENTS IN DANGER
  - of masking / ignoring other possible dx.
  - of the complications of the medications and the IV themselves.
- The current bill will not Δ the practice of Medicine.
- I URGE YOU TO SUPPORT THE PRACTICE OF EVIDENCE - BASED MEDICINE

and to REJECT HB 1326

my testimony is
thought For those that ~~are~~ live Lyme without a Diagnosis [illegible] disease state

HB 1320

File

Statement for Lyme Hearing:

As my testimony reads I ~~[illegible]~~ take 11 [illegible]

I never ~~fathomed~~ in my wildest dreams that ~~it~~ would ~~take 11~~ months for me to finally be diagnosed ~~with Lyme. 11~~ months to finally get one course of antibiotics! All because my first Lyme test (ELISA) was negative and then my second test (Western Blot) was CDC negative. No matter how much the CDC writes on their web site that lab tests should not be used solely to determine the diagnosis of Lyme -that it should be a clinical diagnosis – it is happening because doctors are too busy and depend on those lab tests to be accurate. @ Least 4 yrs [illegible] Lyme

Months of 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 in my ear, muscle aches, unexplained bruising, shortness of breath just walking up a few steps, short sharp intakes of air out of nowhere, exercise intolerance, dizziness, insomnia and extreme fatigue.

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

How do you try to explain to other people what it feels like every morning (after months and months of symptoms) to wake up knowing your ~~day will be~~ exactly the same as the day before and the day before that. Like the movie "Groundhog Day". In the beginning of ~~your~~ "undiagnosed illness" just like the main character of the movie you keep thinking that you will have a new day when you wake up. Then after awhile you would just accept even that you will feel a little better when you wake up. Like having the flu, you come to accept that you feel terrible, but yet you know eventually it will go away, and you will wake up again to that feeling of a new day. Only...to finally come to the acceptance at some point over the days and months that drags on that you will wake up with the same body devastating illness just like all the other days before that. A chronic condition, an undiagnosed illness. How can you explain that to someone else? Interesting for me Almost everyone [illegible] Lyme

April 2006, almost 11 months since my symptoms began, ~~I finally figured out~~ what I had. I found out that Lyme tests are not always accurate and I gave Lyme another look. A family physician with a personal family history of Lyme clinically diagnosed me 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; then replaced by the fear that many never get over Chronic Lyme; then months of antibiotics and illness caused by the antibiotics themselves. I was on consistent antibiotics ~8 months.

Now, it is January 2010, s/p antibiotics 3 years. 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 up Mount Washington June 2008. This was from a woman who could not climb 3 steps without being out of breath ~ 1 1/2 years before. All the heart symptoms that I feared were heart disease are gone now.

Many are not as lucky as I, many suffer for years because of the current inaccurate Lyme tests, others that are diagnosed are denied longer term antibiotics they so desperately need because of the current IDSA guidelines. If I was not lucky enough to have found a doctor who was willing to do a clinical diagnosis, and give me the antibiotics I so desperately needed, I don't think I'd be here right now.

I personally do not know how long someone should be on antibiotics, the magic time frame. What works for one person may take longer for another. As I have already said I was on consistent antibiotics ~8 months (May 15, 2006 –end of December 2006). I do believe though that the longer term antibiotics saved my life.

Please do not take away a doctors 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

Better Question
How many people
had 3 weeks of antibiotics
it was not enough

Complete Document

Can Be Viewed

In Bill Folder

ELISA

Definition

ELISA stands for enzyme-linked immunoassay. It is a commonly used laboratory test to detect antibodies in the blood.

Alternative Names

Enzyme-linked immunoassay; EIA

How the Test is Performed

Blood is typically drawn from a vein, usually from the inside of the elbow or the back of the hand. The site is cleaned with germ-killing medicine (antiseptic). The health care provider wraps an elastic band around the upper arm to apply pressure to the area and make the vein swell with blood.

Definition

Lyme disease antibody tests are used to help diagnose Lyme disease.

Alternative Names

Lyme disease serology; ELISA for Lyme disease; Western blot for Lyme disease

The laboratory specialist will look for Lyme disease antibodies in the blood sample using the ELISA test. If the ELISA test is positive, it must be confirmed with the Western blot test.

Interpreting the IgG & IgM Western Blot For Lyme Disease

WORK IN PROGRESS!!!

The IgG and IgM Western Blot provides results in a way that lets us visualize the patient's antibodies. It is more sensitive and specific than the ELISA and EIA (that is, it is more likely to show positives where the ELISA/EIA showed negatives). The IgG and IgM WB should always be used when the Lyme IgG/IgM antibody serology has returned an equivocal or positive result.

If the patient is highly symptomatic of Lyme, there is actually no point in doing the ELISA or EIA serum tests, as they do not have the sensitivity or specificity of the Western Blot that is needed to have a prayer of detecting *Borrelia burgdorferi* (Bb), the organism that causes Lyme disease.

In a sane world, wherein the CDC and AMA really did their jobs in protecting the public

I am here today to testify in honor of those people who ~~has~~ are sick c̄ Lupus & do not know it yet. If it can happened to me it can happen to anyone. I wish the [illegible]

I never thought

With all due respect

Fuel D[illegible]

[illegible]

Jacqueline Arlen
HB 1326 1

My name is Jacqueline Arlen and I am here today to introduce to you my hero….my daughter Victoria. She has an advanced chronic tick borne infection and according to the AMA what ailes my daughter does not even exist.

I think it is important that you understand what has gone on with our dear sweet Victoria these last five years. She has completely lost these years of her childhood years that she will never get back and has suffered more than any of you can even begin to imagine.

It all started in March 2005 when she was bitten by a tick. I had brought her to her pediatrician because of a red swollen ear and was given cortisone cream and sent on my way. I would find out later on what was written in her chart….small puncture wound visible…possible bug bite. That following year she was plagued with the flu, high fevers, fainting spells, exercise induced asthma amongst many other strange ailments. As you are aware Lyme disease is very curable if a course of antibiotics is given at the onset. Her symptoms were classic but missed. She was back at her pediatricians every other month…this from a child who at most went once a year for well check ups. Because we never knew there had been a bite we just assumed that for whatever reason her immune system was just 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 roll student.

Jacqueline Arlen ②
NB1320

On April 29th 2006 Victoria woke up in insane 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 a few weeks she lost fifteen pounds and her legs started to give out on her. By the middle of June she was unable to walk and we were ordering a wheelchair. She was starting to have trouble swallowing and we were slowly losing her cognitively. All the while she had insane pain on her right side 24 hours a day. Her pediatrician who had had her since birth and missed the very obvious said she was doing it for attention because she is a triplet. 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. After four stays in major medical institutions the doctors were of no help and after minimal testing `unbeknownst to us they were 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

Jacqueline Arlen ③
HB1320

diagnosed by a prominent local Lyme specialist and started treatment.

What is amazing to me is that we acknowledge that early Lyme disease exists and that a course of antibiotics should work to cure it yet we do not acknowledge the cases like Victoria that are missed and turn chronic.

~~I have 3 min not~~ [illegible]

~~I do not have~~ three hours to tell you our entire tragic [illegible] journey and all of her debilitating symptoms but what I will say is because of her infection a recent MRI revealed a blockage on her thoracic spinal chord called post infectious transverse myelitis……. and she is paralyzed from the waist down. A spect scan has shown inflammation throughout her entire brain and she is still fed via GJ tube.

I challenge any one of you to look into my daughters eyes and tell her what she has does not exist.

Thank you for your time.

June Cormier
HB 1326

From:
June Cormier
183 Critchett Road
Candia, NH 03034
January 11, 2010

Testimony regarding House Bill 1326:

I am here today to strongly support House Bill 1326. The time has come to do what is best to help Lyme Disease patients regain their health *and* allow their physicians to offer them the very best treatments, based on the most current information. We must allow our doctors to use their expertise and clinical judgment. This has been the foundation of medicine since the very first doctors began caring for patients.

Here is a synopsis of my experience with Lyme. After two years of multiple symptoms with no real answers, I finally reached a point in May of 2009 which I was unable to work or go about my activities of daily living. I developed encephalopathy, which caused foggy thinking, confusion, impaired memory, headaches, anxiety and periods of rage. This was accompanied by significant joint pain, muscle aches, extreme, debilitating fatigue and ringing in my ears. I work as a nurse with critically ill patients. I was forced by my illness to take a medical leave. At this point I had done enough research on my own to believe that I was suffering from Lyme disease,~~and/or other tick born infections~~. I was a very athletic, active woman with virtually no previous medical problems before becoming

June Cormier
HB 1320

ill with Lyme. I then recalled a round rash on my thigh two years before. I called my primary MD and asked for a Lyme test. I tested positive on the Western Blot for Lyme disease.

My primary MD was not experienced in treating late stage cases of Lyme. I was offered two weeks of low dose Doxycyline. After I completed the Doxycyline, I remained very ill and unable to work. I was offered one more week and told that was all that could be done for me.

I then heard about a doctor in southern NH who is very knowledgeable about Lyme disease. I called his office to make an appointment. It would be two months before I could see him. Finally, I had an appointment with a doctor who understands the complexity of tick borne illnesses and treatment for them. I remain under his care and have been on multiple treatments for both Lyme and co-infections. Although I am still under treatment with antibiotics, I am now working full time and am finally getting my life back. I shudder to think what would have happened to me if this appropriate, research and experience based use of antibiotics had not been available to me.

House bill 1326 is a very important piece of legislation for the people of NH. More and more families in our state are being affected by this illness and it is imperative that we protect and support those medical practitioners who go above and beyond to do what is right for their patients.

Thank you for taking the time to hear my testimony.

Jessica Wojonsai

Lyme Disease Testimonial * Jessica Wojenski * 17 Oriole Drive * Bedford, NH 03110

HB 1326

File

Hi, my name is Jess. I'm 17 years old, and was clinically diagnosed with Lyme disease back in April 2009. But my health battle began long before that... I was diagnosed with many different ailments over the course of 5 years, and at the time, each one made sense for a person my age. Looking back, however, it is clear that all my symptoms fit into an intricate Lyme puzzle, especially for someone who spent as much time outdoors as I did.

My illness started when I was 12, and came down with a severe case of mono that made me miss two months of school. It seemed that my immune system was weakened after that, causing me to get sick more easily than others, especially sore throats. Over my high school years I was diagnosed with things such as a hormonal imbalance, clinical depression, and a high Epstein Barr level. I was put on 100 mg of doxycyclene for a year for severe acne, and all my symptoms subsided. I find it interesting that my ***acne*** could be treated with antibiotics for a year, but that it's so controversial for Lyme to be treated that long. As soon as they took me off the doxy, things went downhill fast. I was terribly depressed and exhausted. I know some people thought I was just lazy, but I've always been active so my parents knew there was something very wrong.

It wasn't until I began to suffer from severe headaches, neck aches, light sensitivity, and painful joints, that our family physician suspected Lyme disease. I have come to find out how lucky I am that he could clinically diagnose me, because all three Lyme tests came back indeterminate. We started antibiotic treatment based on my symptoms, and after an initial Herxheimer reaction, I **started** feeling better. Again, fortunately for me, our doctor understands that it may take a lot longer than 4 weeks of antibiotics to treat a Lyme patient. If he had followed the CDC guidelines, I hate to think how sick I would still be. And when I think back on how hard it was to diagnose, and the relief I felt when I could finally put a name to all my sickness, it is frustrating to realize that some people will never know that feeling. It's even worse to think that some people will never be able to recover as I have, because they were told that 2-4 weeks of antibiotics was all their doctors could do, since they don't recognize another standard of care.

It has now been nine months since I started treatment, and the improvement is obvious. I've gone from being able to attend school only 1-2 days a week to missing only 1-2 days. But by the end of a full week I am often back in bed until Monday. This is ***not*** how I pictured spending my senior year of high school! I'm not even sure I'll be able to start college next year, although I did apply. One of the hardest parts has been trying to explain to my friends what I'm going through, because when I do go to school everyone says, "Well you *look* fine, you don't *look* sick…" And it's true that with Lyme disease you often don't look as sick as you feel. But still, the only exercise I can handle consists of changing classes and getting up and down stairs at home, even though I used to ski and run. I used to be a straight A student, but I've had encumbering cognitive issues, and that combined with missing over 50 days of school because of Lyme has impacted my schoolwork greatly.

It took a very astute, lyme-literate doctor to recognize what was going on, and treat me accurately based purely on my symptoms. I am confident saying that I would not be where I am today if it was not for this. If anything ever happens to our doctor to prevent me and others from receiving the rest of our treatments, I'm not sure what I'll do. The girl standing here before you here today is one who feels like she has finally gotten her life back. And it is absolutely terrifying to think that a relapse from lack of treatment could so easily take that all away again.

But a <u>year</u> later you may start to feel better.

Yes it wells itself into
yes it is persistent

<u>chemo?!</u>

Lyme Disease Testimonial * Jessica Wojenski * 17 Oriole Drive * Bedford, NH 03110

Thank you for the opportunity to speak.

① Hi, my name is Jess. I'm 17 years old, and was clinically diagnosed with Lyme disease back in April 2009. But my health battle began long before that... I was diagnosed with many different ailments over the course of 5 years, and at the time, each one made sense for a person my age. Looking back, however, it is clear that all my symptoms fit into an intricate Lyme puzzle, especially for someone who spent as much time outdoors as I did.

Be in ~~bed for weeks~~ ~~to make~~ maybe a flu disease or 2 follow, but it is anything but fun to wait

I wouldn't be here today — if I had not recieved long-term anti- treat- ~~written testimony — my story~~.

My illness started when I was 12, and came down with a severe case of mono that made me miss two months of school. It seemed that my immune system was weakened after that, causing me to get sick more easily than others, especially sore throats. Over my high school years I was diagnosed with things such as a hormonal imbalance, clinical depression, and a high Epstein Barr level. I was put on 100 mg of doxycyclene for a year for severe acne, and all my symptoms subsided. ~~I find it interesting that my *acne* could be treated with antibiotics for a year, but that it's so controversial for Lyme to be treated that long.~~ As soon as they took me off the doxy, things went downhill fast. I was terribly depressed and exhausted. I know some people thought I was just lazy, but I've always been active so my parents knew there was something very wrong. and stayed in bed as much as I could.

It wasn't until I began to suffer from severe headaches, neck aches, light sensitivity, and painful joints, that our family physician suspected Lyme disease. I have come to find out how lucky I am that he could clinically diagnose me, because all three Lyme tests came back indeterminate. I never saw a tick or had a rash. But ~~the~~ they are prevelent in my ~~area~~ neigh- My Mom also has Lyme disease. We started antibiotic treatment based on my symptoms, and after an initial Herxheimer reaction, I **started** feeling better. Again, Fortunately for me, our doctor understands

② that it may take a lot longer than 4 weeks of antibiotics to treat a Lyme patient. If he had followed the ~~CDC~~ IDSA guidelines, I hate to think how sick I would still be. And when I think back on how hard it

All I can say is thank God she's not our doctor;

~~I've been sick for 5 years. By last year I could hardly get out of bed.~~

The waiting list for my doctor is 3-4 months because he is one of the only ones we know ③ that treats Lyme. That is a long time to wait when you are in that much pain. I almost had to visit a doctor in NY simply B/C I could NOT get an appointment to discuss my next phase of treatment.

You could just say: You ~~have a copy of my~~ written testimonial. I wouldn't be here today if I hadn't received long term ② antibiotics.

How sick would you be right now
This may be a fun disease to follow
but it sure isn't fun to have.

④ was to diagnose, and the relief I felt when I could finally put a name to all my sickness, it is frustrating to realize that some people will never know that feeling. It's even worse to think that some people will never be able to recover as I have, because they were told that 2-4 weeks of antibiotics was all their doctors could do, since they don't recognize another standard of care.

-3-4 mo. waiting list -visit Dr. in NY b/c I ~~[illegible]~~ couldn't get in to discuss the ~~[illegible]~~ next phase of treatment

⑤ It has now been nine months since I started treatment, and the improvement is obvious. I've gone from being able to attend school only 1-2 days a week to missing only 1-2 days. But by the end of a full week I am often back in bed until Monday. This is ***not*** how I pictured spending my senior year of high school! I'm not even sure I'll be able to start college next year, although I did apply. One of the hardest parts has been trying to explain to my friends what I'm going through, because when I do go to school everyone says, "Well you *look* fine, you don't *look* sick…" And it's true that with Lyme disease you often don't look as sick as you feel. But still, the only exercise I can handle consists of changing classes and getting up and down stairs at home, even though I used to ski and run. I used to be a straight A student, but I've had encumbering cognitive issues, and that combined with missing over 90 days of school because of Lyme has impacted my schoolwork greatly.

It took a very astute, lyme-literate doctor to recognize what was going on, and treat me accurately based purely on my symptoms. I am confident saying that I would not be where I am today if it was not for this. If anything ever happens to our doctor to prevent me and others from receiving the rest of our treatments, I'm not sure what I'll do. The girl standing here before you here today is one who feels like she has finally gotten her life back. And it is absolutely terrifying to think that a relapse from lack of treatment could so easily take that all away again.

Karen Dudra
HB 1328
File

How do I describe the journey from one of Dante's hellish rings in *The Inferno* back to a place of relative health?

In late 2006 I began to fall ill with neurological symptoms of twitching, tingling, numbness in my face, seizures and at night—all night long—buzzing in my entire body like a florescent light about to go bad. Cognitive difficulties emerged. I'm a former high school and college English instructor and a writer, but I began to lose the ability to retrieve words--simple words. Then I began to transpose letters. I called my husband of 30 years "Dob" instead of "Bob." Suddenly, I could not concentrate and complete the simplest of tasks. I zigzagged around the house randomly with everyday tasks like brushing my teeth or showering becoming mountains to scale. I felt as though my brain was socked in with impenetrable fog. Most of the time, I felt like I'd fallen in a deep well. My husband would ask a question and I could hear the question, but I was unable to formulate the words to answer him. It took Herculean effort and time to answer. At other times, I could comprehend but was not able to speak and sat staring. I stared a great deal, and I remember that it felt good to stare.

Time passed. Following brain scans, MRI's and countless blood tests, Dartmouth Hitchcock ruled out MS. As I lost 20 pounds and dropped to 95, with muscles wasting and a concentration camp silhouette—my primary care physician looked everywhere for cancer.

The months dragged on. My husband was exhausted. Each day I prayed to live until nightfall. Between April and July of 2007, I had 2 near-death experiences. My 79-year old mother came to care for me. I told my doctors that I felt I had a systemic infection of some sort, and if they would just try me on an antibiotic, I felt I would be helped. My primary care physician replied, "I like to know what I'm treating." I received no antibiotic.

On a brilliant warm day in June, I experienced low blood pressure and photosensitivity so extreme that my husband took me to Dartmouth Hitchcock's emergency room. I had to enter the hospital blindfolded and wrapped in a blanket. My temperature was 96 and my blood pressure was 60/30. The Emergency Room doctors did not know what was wrong, and they did not admit me.

Finally, someone in the wellness field heard my story and gave me the name of a nurse-practitioner who specializes in bacterial infections. The first time she saw me, she urged me to get a Lyme test. I'd had 2, I replied. She pressed on. Which labs? A month later, my blood work was sent to IGENEX in Palo Alto, California. When the test came back, I had my diagnosis: I was highly positive by the CDC standards and the State of New York for an old Lyme infection. What I was dealing with was an untreated, advanced case of Chronic Lyme Disease. The nurse practitioner told me that the first time she saw me, she was certain I had Lyme Disease because my multi-systemic symptoms aligned perfectly with those of Lyme.

You might think the next steps would be easy. They were not. I was so ill that the nurse practitioner could not treat me and felt I might need IV therapy. She suggested I see a doctor who followed the ILADS (International Lyme and Associated Diseases Society) guidelines for treatment, and suggested a doctor in Massachusetts. He did not put me on IV, but on Tetracycline. After 4-6 weeks of treatment, the length prescribed to physicians by the Infectious Disease Society of America, I was starting to show signs of improvement, but clearly, the years of systemic involvement by the Lyme bacteria had created such a bacterial load that I would need more than 4-6 weeks of antibiotics to recover my health.

Following 3 months of treatment in Massachusetts, I began to look for an ILADS physician in New Hampshire to treat me. I was unable to drive myself to Massachusetts and needed a doctor closer to home. Through an underground network, I was given the name of a doctor who treated Lyme patients. Why underground, you may ask? With state medical boards in Connecticut and other states persecuting doctors who prescribed long term antibiotics for Lyme patients, you had to be careful. Word had it that some MDs in New Hampshire who followed the ILADS Treatment Guidelines were being reported by other MDs who did not understand the complexity of Lyme Disease.

And so, I began 9 months of treatment by a compassionate doctor here in New Hampshire. Because Lyme bacteria are stealth pathogens that change from one form to another, it's necessary to use various antibiotics to kill the bacteria in their respective stages. For instance, in one form, the bacteria become a tiny cyst that encloses itself in a tough protective shell. Only one family of antibiotics can penetrate the wall and kill the bacteria. The problem with Chronic Lyme is that the bacteria are in different forms at the same time throughout the body, so there is no silver bullet.

With each antibiotic and the lowering of the bacterial load, my symptoms began to subside. "It's like peeling the layers of an onion," I was told. And so it was. Further testing revealed that Lyme wasn't the only infection I'd contracted from the ticks that had bitten me over the years. I also had a Bartonella-like organism and Ehrlichiosis. These, too, succumbed to treatment. At the same time I was taking antibiotics, my doctor wisely urged me to take probiotics and supplements. I did so and was not adversely affected by the antibiotics. Gradually, through antibiotics, probiotics, and immune-building supplements, combined with careful diet, a variety of alternative healing modalities and thousands of hours researching the disease, I am largely recovered.

Today, though I remain ever vigilant for returning symptoms, I have my life back. More importantly, I view myself as a person who is well. Many people supported me in my difficult journey, but there are two I would most like to thank: the first, the Nurse Practitioner who recognized my symptoms and used the right lab (Igenex) to diagnose my Lyme infection; the second, the doctor who treated me here in NH. I have no doubt that the use of multiple antibiotics over a period of more than a year restored my health and truly saved my life.

You are representatives of the people in a state that is in the cross-hairs of an advancing pandemic. I urge you to vote to protect our Lyme literate doctors so they can be free to treat--without fear--your friends, your family and your fellow citizens. As someone who has walked in the valley of the shadow of Lyme Disease, I can state with certainty that had I not found a doctor willing to treat Lyme disease with long-term antibiotics, I do not believe that I would be here today. I implore you to recommend the passage of HB #1326.

Karen Dudra
90 Old Dublin Road
Hancock, NH 03440
kdudra@comcast.net

HB1320
File
Care Tuttle

Jan 12, 2010

Health, Human Services and Elderly Affairs Committee
House Bill 1326
AN ACT relative to the use of long-term antibiotics for the treatment of Lyme disease
Public Hearing: 1/28/2010 10:00 AM LOB 205

As a victim of Lyme Disease I am writing this letter in support of New Hampshire House Bill 1326 which will authorize licensed physicians to prescribe long-term antibiotics for therapeutic purposes to patients diagnosed with Lyme Disease.

There is a narrow window of opportunity in which to treat Lyme disease. If you happen to be one of the lucky individuals who present with a bulls-eye rash after finding a tick attached to the skin, then your chances of complete recovery is excellent. Unfortunately, the bulls-eye rash appears less than 50% of the time as in our family's case and now our entire family is being treated for Lyme. Lyme Disease is the last thing a primary care physician will suspect as very few are "Lyme literate" even in an area where Lyme is endemic.

My case began in 1996 when at that time a prestigious Massachusetts 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 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 twelve 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 (8 months) for chronic Lyme disease and now her so-called "Fibromyalgia" is non existent. I would like to point out that her 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 bite 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.

As we investigate further we have found six confirmed cases of Lyme Disease within a two hundred yard radius of our home in Hudson. A recent CDC deer tick study found that 77% of Litchfield deer ticks carry Lyme bacteria. On February 11, 2005 the Centers for Disease Control and Prevention issued the following caution: "*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.*"

Physicians in this "*endemic area*" as we have experienced are not familiar with the clinical manifestations of Lyme especially when the patient does not present with the typical bulls eye rash or recall experiencing a tick bite as is the case 50% of the time. My daughter's primary care physician called to inform her that she didn't have Lyme disease based on lab results alone without considering clinical symptoms whatsoever.

Our family is being treated by a Lyme literate doctor who we are grateful. Please support House Bill 1326 intended to protect doctors 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.

Respectfully,

Carl W Tuttle
33 David Dr
Hudson, NH 03051
(603) 479-4927

File Laura Grandis
HB 1326

My name is Laura Grandis and as a longtime resident of NH, I thank you for your time today.

I would ask that you take a moment to envision a **truly** complete life. A life filled with family, friends and an accomplished career… a life that abruptly changes as you begin to experience symptoms that completely consume your life. Pain so intense it brings tears to your eyes, fatigue so severe that from the moment you wake up, you pray the day passes quickly so you can crawl back into bed. But today, I am not here to tell you how debilitating this disease can be, or how it can take months or years to be diagnosed… that needs to be discussed at a different time. would

I have been asked to speak to you today, as my **personal** experience is a testament to how the continued use of antibiotics **CAN** create a successful outcome.

I have had Lyme dis ~~for~~ 10 yrs…

Three years I ago, I was diagnosed ~~with lyme disease~~ and every day for the last 3 years, I have relied upon a variety of medications. Medications to manage my symptoms, but most importantly, antibiotics that every day **PROVE** to be **necessary to fight** this disease.

Daily I am reminded of two things… how fortunate I am to have access to antibiotics **AND** an insurance co that continues to pay for them. Most patients are not so fortunate and that is **exactly why we are here today**. I can assure you that if I had not had access to this treatment, I would not have the physical or mental capacity to speak to you today. Without proper treatment, I was headed for disability from the medical sales job that I have succeeded at for over a decade.

Ironically, my entire career has centered on the prevention of infectious disease. I spend my days working with physicians and public health officials - all in an effort to keep NH residents healthy. Because of my background I am very familiar with the "evidence based medicine" that discusses the potential risks of antibiotic use. Despite all the studies and for reasons unknown, I **CAN** tell you that **EVERY** time I have tried to stop my medications, my symptoms have **ALWAYS** returned. So for someone who clearly understands "what ifs", I would **ABSOLUTELY** risk **ANY** side effects as **antibiotics have PROVEN** to **DIRECTLY** impact **MY** quality of life.

So the decisions you contemplate today involve a number of factors: you are looking at costs, risks and benefits…

Certainly there is a **tangible cost** with the long-term use of antibiotics.

I would ask though that you look beyond this and focus on factors that **CAN NOT** be measured.

Look instead at the cost when a **mother or a father** is **SO** ill that they no longer can care for their children?

What is the cost when an **employee** can no longer perform their job and thus support their family?

What is the cost when a **parent** is helpless to find treatment for their child who is suffering from this disease?

These risks… these costs… they can't be measured.

I would just ask that you consider the question,

"*What dollar amount would **YOU** put on the **loss of hope***
*if **YOU** were the patient unable to receive treatment*
*for a disease that was consuming **YOUR** life?"*

So on behalf of every patient and family here today, **I respectfully ask that YOU support legislation removing ANY barriers that prohibit access to these antibiotics.**

Thank you for your time.

Erin Fallon
HB1320
File

- 50 yrs old, resident of Strafford 21 yrs. Married 28 yrs... 3 children ages 20, 24, 27.

- Self and all 3 children tested + for lyme disease with a long history of symptoms./All have been treated with long term abx./Two managing minor symptoms now with healthy lifestyle./20 yr old son recently relapsed after 2 yrs off abx, and having cognitive problems again that are interfering with his college education.

- Drs. have suggested that my children were born with lyme, based on scientific evidence that 2 of them and myself tested + for the same strain of lyme. Lyme has been consistently found in cord blood and breast milk.

* I have had to battle w/ my insurance co. repeatedly for treatment, including having to report to the state ins. commission

- I grew up in rural CT. I had multiple tick bites with bull's eye as a child. In middle school I began having vision problems, bone and muscle pain./By high school I had chronic bone issues, chronic sinus infections and pneumonia./College brought me a broader view of the world, and chronic tonsillitis, resolved after 2 yrs with surgery, bursitis in both hip, not relieved by cortisone injections, and the kicker was a diagnosis of non-articular rheumatoid arthritis for which the prognosis was being wheelchair bound.

- I'm not in a wheelchair./5 yrs ago while in graduate school after yrs of pain and seeing multiple medical professionals while living in Pittsburgh, Ct and then NH, I developed memory loss/I was diagnosed with lyme disease, and sent to see and experienced lyme literate Dr in Ct because my NH Dr. who had little familiarity with lyme didn't know anyone Dr in NH who could treat my advanced symptoms.

- I have taken 14 months of IV abx, as well as a couple of yrs of oral treatment to address the problems of lyme and co-infections./Along with lyme I have multiple autoimmune diseases and currently receive weekly infusions of immunoglubulin, which keeps me alive./I have residual nerve damage and stay on seizure medication daily./Last yr I finally gave up hope of turning that last corner to getting back to work and school, gave up my pride and applied for disability./I receive SSDI checks and medicaid benefits which helps slightly with my medical bills.

- My son and I still travel to CT every 10 wks to see our Lyme Literate Neurologist.
  The travel is physically and emotionally wearing.

- It's unfortunate that Lyme disease can become chronic if not caught early, and that it can effect so many areas of the body./I feel blessed that I have been able to find wonderful Drs. with years of experience treating chronic lyme who have helped me and my family./Unfortunately, these Drs. could not practice in NH even if they wanted to right now because of the hostile medical environment./The NH medical community needs to acknowledge that chronic lyme exists and that there are two scientifically proven standards of care.

- *I urge you to vote into passage house bill 1326 to protect NH Drs. who choose to treat lyme disease with long term abx and see their patients heal. Thank you,

File Julie Hall
HB1326

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 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 became symptomatic with Lyme Disease again in 2007 after being diagnosed and treated with a conservative course of antibiotics in 2004.

Tucker, who two years ago had to be carried to the bathroom, missed five 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. and were hesitant to consider or treat according to the ILADS standard of c

Yes, my Tucker, who is well today. So well, in fact, that he could not be here today because he is up north, competing on Exeter High School's Varsity Ski Team and hoping, like any other kid his age, that he won't blow out of the GS gates. I want to tell you his story, because two years ago, nothing that Tucker was doing was like other kids his age.

My son was originally diagnosed with Lyme Disease in 2004 when he had flu-like symptoms, lethargy and six bulls-eye rashes. Classic Lyme. Our doctor, following the guidelines set forth by the Infectious Disease Society of America, prescribed three weeks of antibiotics. I thought all was fine. That winter he became symptomatic again. He was put on a course of 12 weeks of antibiotics, as our nurse practitioner recognized that the Lyme bacteria had probably not been eradicated. She was right, but by then it was too late.

Intense [illegible]

Tucker developed symptoms again in 2007. Stomach pain. Intestinal pain. Headaches. Dizziness. Our doctor thought it was a flu. 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 we have. 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 our 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.

I didn't know there was another set of guidelines to be considered

When he couldn't walk anymore because of chronic knee and ankle pain, a new New Hampshire doctor said, now this looks like IDSA Lyme. A specialty lab confirmed the diagnosis. But he didn't feel comfortable treating my son. He sent us to Connecticut. "You need to see this doctor," he said. "He's treated more than 10,000 cases of pediatric Lyme, 90 percent of them successfully."

And so, we went. That day, ~~Dr. Jones~~ my doctor spent four hours performing a clinical evaluation. I felt like I had finally found a soft place to land. Somebody who "got" all that we had gone through. "You're fix-able," he declared to Tucker. And my son smiled for the first time in months.

A clinical evaluation determined that Tucker was, in fact, suffering from chronic Lyme, something other doctors refuse to believe even exists. Further CT-scans, and biopsies of his organs indicated that the spirochetes had impacted his brain, his organs,etc. The spirochetes that cause Lyme had, in fact, been festering in his body for years ... and he was one sick boy.

He was put on a long-term regiment of oral and IV antibiotics, which I infused daily. I still remember the day, months after the fearful first infusion, that Tucker walked into the living room of his own accord, and told a joke. I knew, then, that my Tucker was "in there." He was coming back.

despite cost insurance stopped covering - $5,000/month

he never had an infection his gall bladder was monitored carefully during his IV treatment 5 mos Feb- 2009

Tucker has come back. stopped all Rx in ~~antibio~~ August & no longer symptomatic And the only reason he has, is because we found a doctor who was trained in Lyme and was willing to treat my son. A doctor who, I might add, has been in court fighting to retain his medical license for years now.

The rest of my family has been lucky. For had it not been for Tucker's story, we would not have discovered that there are, in fact, two standards of care and that we could choose to seek aggressive oral antibiotic treatment the first time we were infected. I am still amazed when I think the the IDSA guidelines that many doctors refer to, tell physicians not to prescribe long-term antibiotics because of fear of resistence. 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 to the use of prolonged courses of antibiotics for young people with acne. ~~or even an~~ Animals receive more antibiotics the

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 be utterly dogmatic, either.

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 stuck by me 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, before you vote to move this forward or not, remember the faces of the patients you have heard from today. And think of my son, flying through the gates today, with a wide smile on his face. Thank you.

lead the way
States passing ~~the bill~~
or considering
passing similar legislation

File 1
H/B 1326
Marilyn Rivera

Hello,

My name is Marilyn Rivera, I live in Strafford NH and I too have Lyme disease. It's quite possible that I contracted it before I had my children and passed it to my daughter while pregnant.

I was on antibiotics for 18 months and am happy to report that I was recently taken off all my medications, and I'm doing great.

My family physician didn't think I had Lyme because I'd never seen a tick on me, but I explained about a strange bite I had years ago so he agreed to have me tested.

That test came back negative so I asked to have a more extensive test called the Western Blot, which is done through a lab in California, but my doctor refused even though I offered to pay for it myself.

I went to see a thyroid doctor who agreed to order that test and also a CD57, a test which determines how well my immune system is working. Both tests indicated some Lyme activity so he put me on 3 weeks of antibiotics, but that was all I could get.

Because my daughter had been so sick for so long I wanted her tested as well, but our doctor refused to order a CD57 because he did not know what that test was. Finally after a 45 minute discussion he agreed. He

said, "OK, I'll order the test, but you have to take it to someone else to interpret because I don't even know how to read that test."

A couple of weeks later I received the results in the mail, and written across the form was "Send to mom to interpret." Now, her tests also showed some Lyme activity.

The day before we got the results she was telling me she felt her muscles were going into atrophy, and a couple of days later she was in a lot of pain, she couldn't walk, and her legs and arms would go numb. Frantically, I took her back to see the doctor, and asked if he would put her antibiotics, but he refused because she too had had an initial Lyme test come back negative.

We went to see two other doctors who also said no to antibiotics. They said she probably had arthritis so I should take her to see a rheumatologist and a neurologist so she could be evaluated for MS. One doctor even wanted to put her on steroids. These doctors made me feel like I was a hysterical mom who didn't know what I was talking about.

At one point my poor child was put on medication for depression, she was taking something for anxiety, another medicine for ADD, something to help her sleep, and was even given long-term antibiotics for

acne, but no one would treat the Lyme, which we now know was the culprit of all her problems.

Finally I found a Lyme literate doctor who is two hours away. My daughter is on her second year of treatment and is doing much better.

I am so grateful for this treatment and that is why I come before you today to ask you (no to beg you) to please, please support this bill so that if some day you or someone you love comes down with this horrible disease you won't have to endure what we had to go through.

Thank you

if antibiotics are so dangerous then why can teens be on it for years for acne

Jessica

are you gonna speak on how IDSA
is on insurance Boards

** ——— Being Watched by Medical Review B.

NH medical Society
Janet H. Monohan

Diff. bet what IDSA recom.
+ what ILADS Recom.

Tetracycline
Amantadine
Winter

The cause for standards is due to:

Summer:
Chlorythimiacin
Plaquanil

Egos
Insurance Co.
+ Politics

Dr. Susan Sabateer

The Evidence is in the fact that we are better!

Andrea Martel
File HB 1320

Dear Respected Organization,

My story officially begins on February 10, 2009. I use the term officially because I, like so many others, went undiagnosed for many many years. Since my childhood I have experienced unexplained pain and illnesses.
At the age of 11, I started to experience knee pain that was so excruciating, I could not sleep at night. The pain became so unbearable, I was forced to see a Physical Therapist 3 times a week for several months. While most kids my age were out playing sports, enjoying the warm weather, I was inside 3 nights a week for 2 hours at a time working with a PT. During this time, no known cause was provided for my knee issues.
At the age of 13, I started to experience migraines and what seemed like ulcer-related symptoms in my stomach. My migraines caused me to miss many days from school and directly affected my schoolwork.
Over the course of the next few years, other issues surfaced. Severe fatigue, constant sore throats, cognitive issues, heart palpitations, etc. Throughout my entire schooling up to grade 9, I was a straight A student, with a few B's here and there. Starting with my freshman year in High school, I noticed things were not coming as ~~easy~~ easily! I struggled to retain knowledge from classes and apply them to my school work. What would normally take me an hour or so time for homework, was now taking double the effort. I just chalked it up to being in high school and the work getting harder. I slowly saw my GPA of 3.6 drop down to 2.8. I went from feeling smart, to feeling like I wasn't worth anything. I was very hard on myself and knew I could do better, but no matter how much I tried, or how much I studied, I lacked focus and the ability to retain. ~~[illegible] now there are programs in school that allow time off for such issues, i.e. 504 Pla~~n.
My high school years consisted of going to school, coming home and napping for a few hours, barely being able to eat because of stomach pains, going back to bed early.
I missed out on a lot due to my illness. I was constantly in and out of my PCP's office.
Graduating high school was a great achievement for me, however, I always pictured it would be with honors.
Once I got into College my cognitive thinking really started to become one of my major issues. Because of that, during my second year, I regretfully dropped out. The stress and great effort it was taking to merely pass a course became too much. My health really started to become a downward spiral.
Now, 15+ years later, I have found an answer to all my health issues and a Doctor that wanted to see me through to the end and to see me become healthy again.
In a month, it will be a year that I've been on antibiotics. During this time there has been major improvement in my health and abilities. Simple things like cleaning my house now don't force me to stay in bed the entire next day. Had it not been for a Doctor willing to listen to my health concerns and treat me and my symptoms until improvement was made, I know without question, my quality of life would forever be poor and shortened.
Since starting my treatment, I've kept a log of all my symptoms during the day. As time went on, that list got shorter and shorter. About 8 months into treatment is when I started to really notice a difference.
I ask that you please consider bill 1326, without the option of long term antibiotics, I know many lives will be affected.

Thank you for your time and consideration on this bill,
Andrea Martel
Bedford, New Hampshire

File HB 1320

Comments to the House Committee on Health, Human Services and Elderly Affairs
re
State of NH House of Representatives Bill 1326
Thursday, January 28, 2010

by Edward L. Yourtee, MD, FACP
45 Sharon Rd
Windham, NH 03087

Good Afternoon, honorable representatives, ladies and gentlemen:

My name is Edward Yourtee, from Windham.

I am a doctor who practices internal medicine and infectious disease in the Lyme belt of Southern NH. I am board certified in Infectious Diseases and have well over 60,000 hours of continuing study and experience in internal medicine, infectious disease and Lyme disease.

I have a longstanding interest in Lyme Disease. When I did my infectious disease training at Yale (where Lyme disease was discovered), the cause of Lyme disease was still unknown. So I have followed the literature of Lyme disease and its treatment with great interest since its infancy in the late 1970's. I personally treat and consult on many patients with Lyme disease or chronic Lyme symptoms. And I currently perform quality review of cases of Lyme disease and of chronic Lyme disease from throughout the East Coast.

From this perspective, I do not believe the proposed law should be enacted, based on this principle:

Even when medical treatment may need to be regulated, it should not be legislated.

I am well aware of the highly charged debate over prolonged treatment of persons diagnosed with Lyme disease. Insurance companies decline to pay for treatment, and in one or two instances, doctors have lost thier licenses in other states because of habitual prolonged antibiotic treatment for Lyme diagnoses. This law seeks to protect such doctors.

For 28 years, the diagnosis of Lyme disease has been based on typical rash or arthritis plus development of Borrelia(Lyme) antibody. Now this approach has been challenged. A group of "Lyme literate" doctors propose that chronic Lyme disease can be diagnosed based on positive responses to a list of 25 common everyday symptoms, even with negative lab tests. They treat these patients with oral and intravenous antibiotics for months to years. This unusual approach has generated great controversy.

Discouragingly, there is still no good published data showing that prolonged antibiotic treatment helps. There is not yet a published blinded study that demonstrates sustained effectiveness of prolonged antibiotics. There are, however, case reports of deaths complicating prolonged IV antibiotic therapy.

These points are raised to point out that this is a complex area with: many subtleties, firmly held differences of opinion, and not enough facts. This is a rapidly moving field, with high emotion and claims and counterclaims. The line between responsible practice and irresponsible practice remains highly contentious. It does not lend itself to simple solutions.

With great respect to our Representatives, laws can be blunt instruments and more often passed than repealed. Medical treatment should not be based on politics or popularity. The deliberative legislative machinery is not suited to regulate rapidly evolving areas of science. A more nimble regulatory body should oversee this debate. If regulation of Lyme treatment is required to protect patients, it should come from the Board of Medicine or the Medical Society, with appropriately balanced scientific and public input. It should not be regulated by the legislature.

Thank you.

****

The following list of symptoms from ILADS "Evidence Based Guidelines for Lyme Disease" is used as a diagnostic guide for Lyme disease. [I believe these fail to distingush Lyme disease from a myriad of other medical conditions. -ELY]

9. Symptoms of Lyme disease
- Fatigue
- Low grade fevers, 'hot flashes' or chills
- Night sweats
- Sore throat
- Swollen glands
- Stiff neck
- Migrating arthralgias, stiffness and, less commonly, frank arthritis
- Myalgia
- Chest pain and palpitations
- Abdominal pain, nausea
- Diarrhea
- Sleep disturbance
- Poor concentration and memory loss
- Irritability and mood swings
- Depression
- Back pain
- Blurred vision and eye pain
- Jaw pain
- Testicular/pelvic pain
- Tinnitus
- Vertigo
- Cranial nerve disturbance (facial numbness, pain, tingling, palsy or optic neuritis)
- Headaches
- 'Lightheadedness'
- Dizziness

Support Bill 1326 File

Karen Steele, Mechanical Engineer
Atkinson, NH - Rockingham Co.
3 1/2 yrs. ago, diagnosed w/ Lyme by Blood Test
50% houses in my neighborhood → BEAD DELP
4 wks of antibiotics
website - PA → 6 wks, New Dr. → PCP + IDSA
Unable to get more antibiotics
4 wks later Relapsed → Severe, debillitating Pain, Exhaustion, nausea
Re-Tested - 4 More PEAKS → ↳ unable to move my fingers more
Evidence Lyme was growing in my body → doxy
Tried Alan Steere Waited months to see Dr. Kalish
"you've had AB, clearly no Lyme, we'll find out what's wrong"
→ For $10 + 4-8 wks of AB, prevent $5K spend
Husband → Unemployed, cut back on my supplements
Igenex Had Bloodwork in Oct 2008 (2yrs) → still IgM
Self treating w/ Supplements based on my own research
↳ Never found an LLMD ~~that was accepting patients~~
ROOT CAUSE - "Under Our Skin" = Politics Money Power

Long Term AB → Acne → yrs of tetracycline

It's sad that we need a law like this
but we need a law like this
I'm under control, but for my children, please, please
Please let doctors do what they are trained to do → HEAL people
Please ~~make~~ have the courage → Make 1326 a LAW

File HB1326
Douglas Newton

Comments for the Committee on Health, Human Services and Elderly Affairs about HB 1326, relative to allowing physicians to treat Lyme disease with antibiotics for more than 4 weeks without penalty.

My name is Douglas Newton. I am a logger from Warner, N.H. I have Lyme disease.

Why are we here? I have told a few friends that I would be testifying before this committee on a Bill to make it illegal to revoke a doctor's license fro treating Lyme disease. When I tell people this they look at me as though I were crazy. "Of course you wouldn't take a doctor's license away for treating Lyme disease!"

Unfortunately most people don't know the history of this epidemic that was first identified in Lyme, Connecticut. In many states where the disease is endemic, many doctors have lost their license or been forced to stop treating Lyme disease, for prescribing long-term antibiotics and for treating patients who did not have positive Lyme tests.

How can this be? I would like to give you my logger's / Lyme patient's take on how we got here and how this Bill helps us out of a bad situation.

It's complicated, as is the bacteria that causes Lyme, Borrelia burgdorferi (Bb).

In a recent study they collected deer ticks from Maine to Georgia, and found Bb in many of them. They separated the Bb into 20 different strains based on different surface proteins. They found that 6 of the strains would not cause illness in humans; 10 strains caused a rash only, which went away in time; and 4 of the strains make people very sick and give them what we know as Lyme disease.

At the heart of the controversy is a doctor named Alan Steere. He is a rheumatologist who started his career as a medical detective at the CDC before becoming a researcher at Yale. He was the first doctor to take seriously a cluster of juvenile rheumatoid arthritis in Lyme, CT, which is one presentation of what we have come to know as Lyme disease.

Steere and his colleagues developed the idea that Lyme disease was an easily diagnosed, easily treated disease that is cured by a moderate, 2-4 week course of antibiotics. They consider any further symptoms to be an immune response triggered by the disease but not caused by lingering bacteria. This so-called "Post-Lyme Syndrome" often results in a diagnosis of Chronic Fatigue Syndrome or Fibromyalgia. (These two diagnoses were created by Steere and collegues early in the Lyme epidemic.)
This view is held by a group of University-based academic doctors who believe that Lyme disease is over-diagnosed and over-treated.

Alan Steere is viewed by many as the world authority on Lyme disease. He is viewed by others as the "Darth Vader" of Lyme disease, who has sold his narrow conception of Lyme disease to managed care insurance companies who are happy to have a reason to refuse the extended courses of antibiotics that Clinical doctors believe are necessary to treat Lyme after it has become established in a patient. He has testified many times for insurance companies stating that sick people did not have Lyme, or that they no longer had Lyme, but that they certainly did not need extended antibiotic treatment. He has testified against many doctors whose licenses were on the line for overtreatment of Lyme disease. It is because of Alan Steere's narrow view of Lyme disease, which has become the medical mainstream, that we are here today.

There is another view of Lyme disease held by "Lyme Literate" doctors who are clinicians treating patients whose Lyme was not eradicated at the early stage when it is truly easily treatable. This view of Lyme is of a disease that can infect any part or many parts of the body, and is known (like syphilis before it) as the great imitator, for it can resemble many other diseases. This view is of a disease that has natural immunity to some antibiotics, of a disease that often does not result in positive blood tests even when firmly established. This view is of a disease caused by a spiral bacteria that can change the proteins on its surface to fool the immune system, a bacteria that can live in blood or inside cells or in the spaces between cells, or in the brain and nervous system, a bacteria that can lie dormant in protective cysts that shield it from most antibiotics and can emerge virulent when antibiotics are stopped. This view is of a disease that is often complicated by co-infections – other bacteria and protozoans that came from the same tick that caused the Lyme but may not be killed by the antibiotics that treat Lyme. This view is of a disease that is hard to diagnose and hard to treat and which requires long courses of antibiotics to cure once it has become established. The main proponent of this view of Lyme disease is Joe Burruscano, who for many years aggressively treated Lyme patients and who now does Lyme research. His view of Lyme is contained in his "Treatment Guidelines for Lyme Disease" now in its sixteenth edition and available free on the web. www.ilads.org

The CDC tracks infectious diseases. With the help of Alan Steere they developed a definition of Lyme disease for reporting purposes. A case of Lyme disease is reportable to the CDC if 1) it began with a physician diagnosed erethema migrans (bullseye) rash or 2) if the patient has a very specific positive blood test (based on a study by Alan Steere) plus one of the major late symptoms: Lyme arthritis, meningitis, facial palsy, radiculoneuropathy(shooting nerve pains emanating from the spinal column) or heart block.

The CDC has always said that this case definition is for reporting purposes only and should not be used for clinical diagnosis.

In 2007 C. Ben Beard, then head of the CDC department in charge of Lyme disease, said that Lyme cases reported to the CDC were probably about 10% of actual cases of Lyme disease. This is partly because not all cases are reported but largely because many, if not a majority of Lyme cases do not meet the CDC's narrow definition. If the CDC says you have Lyme, then you have Lyme to as close to a medical certainty as is possible. However if you don't meet CDC criteria you may still have Lyme. If you are tracking an epidemic 10% of cases is fine – you can still clearly see where the disease is prevalent or spreading or waning. If you are treating an individual then 90% or even 40% of false negatives is totally unacceptable.

Enter the Infectious Disease Society of America. This group of doctors that includes Alan Steere and many of his colleagues publish "Guidelines for the Diagnosis and Treatment of Lyme Disease." These guidelines embrace Alan Steere's narrow conception of Lyme disease as easy to diagnose and easy to treat, and they establish the CDC definition of Lyme as the clinical standard though it was never intended to be used this way. So, according to the Infectious Disease Society of America:

1) 2-4 weeks of antibiotic will kill it or it isn't Lyme.
2) A patient's blood must be CDC positive or it isn't Lyme.
3) Only "major symptoms" count for diagnosis.
4) Chronic infection with Lyme bacteria does not exist.

This is the mainstream position in American medicine – "the party line."

The IDSA was sued by the Connecticut attorney general who alleged conflict of interest by several members of IDSA as well as failure to follow their own guidelines in establishing that chronic Lyme disease does not exist. ISDA lost and is under court order to revise their guidelines.

IDSA insists that chronic Lyme disease does not exist, despite the fact that every study of Lyme disease in animals (in dogs, mice, rabbits, and rhesus monkeys) shows that once the infection is established, no matter how hard you treat with antibiotics, there are still live Lyme bacteria at autopsy.

My wife received a handout from a Concord Hospital doctor entitled "Diagnosis of Lyme Disease" downloaded from a web site "uptodate.com" that Concord Hospital subscribes to. This publication is edited by Alan Steere and it reflects his narrow definition of Lyme disease and the Infectious Disease Society of America's "Guidelines."

The problem with all this is that many Lyme patients fall through the cracks. They don't remember a rash. They don't pass the CDC blood test. They don't have major symptoms. They don't get the diagnosis of Lyme disease and they don't get treatment, unless they find a doctor who is willing to treat outside the IDSA guidelines and that doctor's medical license is then in jeopardy, which is why we are here today.

In conclusion I quote from my wife's testimony (Nancy Ladd):
"HB 1326 is an essential step in helping to avert a growing health crisis, by allowing doctors to practice effectively without fear of penalty, and to provide treatment to increasing numbers of patients who have a very real need for relief from a severely debilitating or fatal condition. Its passage will also provide support for those fighting to change the guidelines, and those patients unable to get insurance coverage for their medical expenses. Other states have passed similar legislation including Connecticut, Delaware, Maryland, Minnesota, New Jersey and Rhode Island.

I urge the committee to recommend passage of this bill and to educate the legislature about this issue.

Thank you for your time and consideration,

Douglas R. Newton
483 Newmarket Rd.
Warner NH
January 27, 2010

IGeneX, Inc.
795 SAN ANTONIO ROAD
PALO ALTO, CA 94303
(800)832-3200

PATIENT: NEWTON,
DOB: AGE: SEX: F

SAMPLE ID: 287466

DRWN: 12/07/09
RCVD: 12/09/09
PRNT: 12/22/09

DIRECTOR: JYOTSNA SHAH, PhD

Tests performed at 795 San Antonio,P Alto,CA 94303, except portion of process of PCR & RWB which is performed at 797 San Antonio, P Alto, CA 94303

TEST NAME	RESULT	UNITS

LYME IgM WESTERN BLOT .....

REVISED 07/27/09-

IGeneX Interpretation is based on internal validation studies. By IGeneX criteria, IgM WB is considered positive if two or more of the double starred bands below are present. The IgM WB is considered negative if less than 2 starred bands are present. A positive suggests exposure to B burgdorferi. By CDC/NYS criteria, IgM WB is reported positive if 2 of the following bands are present:23-25,39,41kDa. The IgM WB is negative if less than 2 bands are present.

LIMITATION: Positive result for 31 and/or 34kDa may be present after Lyme vaccination in uninfected persons. Infection with HSV,EBV,HCV and/or syphillis (RPR+) may give false (+) results. In a sample set of 165 well characterized specimens with 36% positivity rate, the assay specificity and sensitivity was 96% and 73% by IGeneX criteria; and 99% and 58% by CDC/NYS criteria respectively.

☆ ****PRESENCE OF ONLY ONE DOUBLE STARRED BAND OR INDETERMINATE DOUBLE STARRED BANDS IN A NEGATIVE REPORT MAY INDICATE CLINICAL SIGNIFICANCE.**** THEREFORE, WE RECOMMEND TESTING WITH ANOTHER METHOD AND/OR RETEST IN 4-6 WEEKS.

BAND INTENSITY: Negative (-): No visible band present. Indeterminate (IND): Band present with intensity < Weak (1+) Positive Control. Positive (1+ to 4+): Band present at an intensity >/= Weak (1+) Positive Control.

tives

IGENEX IGM RESULT	POSITIVE
CDC/NYS RESULT	NEGATIVE
18 kDa.	-
22 kDa.	-
**23-25 kDa.	IND
28 kDa.	-
30 kDa.	-
**31 kDa.	++++
**34 kDa.	-
**39 kDa.	IND
**41 kDa.	++
45 kDa.	-
58 kDa.	+
66 kDa.	-
73 kDa.	-
**83-93 kDa.	+

Diagnosis should not be based on laboratory tests alone. Results should be interpreted in conjunction with clinical symptoms and patient history.

End of Report

File HB 1326
Peggy Flanagan

Personal Testimony
for the
Health and Human Services and Elderly Affairs Committee
Re: HB 1326

In May of 2006 my then 10-year old daughter, Rebekah, became chronically ill with what was later diagnosed as Lyme Disease. These are some of the symptoms she exhibited at the onset of the illness:

- Swollen left knee
- Migrating joint pain
- Dizziness
- Headaches
- Continual low-grade fever
- Stabbing, burning, and numbing sensations throughout her body.

We took Rebekah to her primary care physician (PCP*) who ordered numerous tests, including blood work, MRI's*, and a bone scan. He also referred us to an orthopedic doctor and neurologist. The orthopedic doctor suspected Juvenile Rheumatoid Arthritis. He referred us to a specialist in Boston, MA to determine if Rebekah had JRA. The doctor's assessment was that she did not have JRA, however, she could not find an explanation for her pain. The neurologist, after examining MRI results, found her brain scans to be normal. The bone scan was normal as well. The PCP dismissed a diagnosis of lyme disease because blood tests were inconclusive based on CDC standards, although he did start Rebekah on a 30-day regimen of oral antibiotics. After completion of the antibiotics her symptoms did not improve. We returned for a follow-up visit when he determined she had Conversion Disorder- a disorder characterized by the conversion of mental conflict into physical symptoms with no underlying physical cause. My 10-year old daughter's remark to this was, "He thinks I'm crazy. "

As a result of this misdiagnosis Rebekah's condition worsened over the summer. By September she became wheelchair-bound because of her joint pain. After the PCP's diagnosis of conversion disorder, we sought out a doctor who specialized in lyme disease to see if it might be the cause of Rebekah's illness. We found a lyme specialist in southern N.H. After he reviewed results of the tests performed by our PCP and his referrals, and his own additional blood work for lyme, he clinically diagnosed Rebekah with lyme disease.

He started Rebekah on the oral antibiotic doxycycline, but she was unable to continue the medication due to an adverse reaction. At this point, long-term IV antibiotics were considered, but the lyme doctor wanted a second opinion from a pediatric lyme specialist in Connecticut. After we visited the doctor in Connecticut he concurred with long-term IV antibiotic therapy for Rebekah's lyme disease.

In October of 2006 she began this treatment with the drug, Ceftriaxone, which was administered through a PICC* line 2 times a day for an hour each time. Treatment began in October of 2006 and continued until May of 2007, when it was determined by the lyme specialist in Connecticut that treatments could be stopped since she was asymptomatic for six weeks. Without such treatment, the infection caused by the lyme bacteria would not have been eradicated.

This is a brief testimony of the journey Rebekah and our family had to take to identify her illness and find effective treatment that restored her to health. Since May of 2007 Rebekah has had no recurrence of lyme symptoms and leads a completely normal lifestyle.

JRA: Juvenile Rheumatoid Arthritis*

MRI: Magnetic Resonance Imaging*

PCP: Primary Care Physician*

CDC: Center for Disease Control*

PICC: Percutaneously Inserted Central Catheter*

Footnote

In December of 2006 Rebekah underwent exploratory knee surgery at a children's hospital in Boston, MA to assess possible causes for constant knee pain. The results indicated that her knee was structurally sound.

Submitted by Peggy Flanagan, Dover, NH

I WAS TOLD MY SYMPTOMS IDSA SUBJECTIVE, I HAVE OBJECTIVE PROOF! SPECT SCANS, MRI'S, ETC...

WOULD LIKE TO SUBMIT A MICRO PHOTOGRAPH OF LYME INSIDE MY RED BLOOD CELLS!

HB 1326

File

When I first got ill, I was wracked with pain and crippling fatigue. Ridiculed by my Primary Care doctor for 6 months, I was told to "see a shrink". Knowing that I WAS ill, My wife and I deduced it might be Lyme.

BY THE NEUROLOGIST @ DARTMOUTH

The only openly treating Lyme doctor in NH had a 4 month wait. In Boston, it was 6 months! By the grace of God, we found Dr. McNeal and he took us that day.

He diagnosed me with Lyme. For further testing, I traveled 6 hours to NYC and (with the help of our families) paid $7,500 cash to be seen at Columbia Lyme Center.

4 years ago, the Concord Monitor ran an article about Dr. McNeal titled: "For many, it's the last refuge" How true it was! I was quoted as saying: "I'd be totally disabled. I was totally disabled in January." When I first met Dr. McNeal in January, I could barely walk. He helped me regain my health enough to return to work. Unfortunately, he had to close his office and refer me to a Lyme doctor in NYC.

NOT ASKING FOR IMMUNITY OF CONSEQUENCES OF DOCTORS WHO TREAT, WE ARE ASKING THAT THEY WILL BE PROTECTED FROM PROSECUTION

With such a complex illness, all of your doctors need to work as a team. The costs are astronomical and the visits are frequent. It's been very difficult to coordinate my primary care doctor with my Neurologist in Mass, and my Lyme doc 300 miles away in NYC. Long distance treatments are difficult, costly, and unduly complicated. It's especially difficult to get the close monitoring necessary with IV therapy.

SIMPLY FOR TREATMENT

There is also little hope of reimbursement from insurance companies when you seek treatment out of state.

THE TWINS HAVE INVOLUNTARY MOVEMENT. THEY BANG THE WALL WITH THEIR HEADS SO HARD, THEY PUT A HOLE IN THE WALL.

WE PAID $1700 A MO OUT OF POCKET B/C INSURANCE WOULDN'T COVER FOR 4 MOS

I was treated for a while by the doctor in NYC. Due to the afore-mentioned difficulties, I have since relapsed and now I AM [redacted] totally disabled. I was forced to apply for Disability and lost my job. OF 12 YRS.

MY WIFE DIDN'T KNOW THAT SHE HAD LYME AND GAVE IT TO THE TWINS IN UTERO SP?

SARAH 8, BEN 6, AND TWINS: ZACHARY (3), JEREMY (3)

Sadly, my wife and children are ill too. We tried to see a Pediatric Lyme specialist in CT, but the monetary assistance ran dry before our appointment, forcing us to cancel. Not being able to address the cause directly, we've spent 5 yrs treating symptoms. Now we need a team of doctors for all 6 of us!

THIS HB ALLOWS DOCTORS AND PATIENTS TO WEIGH THE RISKS OF TREATMENT.

Some Lyme doctors have been put through unnecessary medical board reviews, and some have even unjustly lost their licenses. Without any specific protections, NH has not been a safe place for Lyme doctors to practice.

We treasure those who have fought tirelessly to have made us well - they are our Heroes! These doctors truly are our "last refuge": Please give them the refuge THEY need to treat their patients without fear of reprisal.

WOULD LIKE TO ENCOURAGE EACH OF YOU TO VIEW "UNDER OUR SKIN"

Thank you on behalf of my family, our doctors, and the Lyme community AND - many of whom are too sick to even be here today.

HOW DOES THIS AFFECT US?

DR MCNEAL WAS ABLE TO TREAT ME WITH IV MEDS, NOW HE WILL ONLY PRESCRIBE 10 DAYS!

JONATHAN GOLUBIEWSKI

OVER →

TO UNDERSTAND <u>WHY</u>?

WHAT IS THE ROOT CAUSE? CORRUPTION OF THE MEMBERS OF THE IDSA. THE ATTORNEY GENERAL OF CT. HAS INDICTED SEVERAL MEMBERS OF CONFLICT OF INTEREST AND MANDATED THAT THE IDSA GUIDELINES ARE PEER REVIEWED. AS PREVIOUS

AS I UNDERSTAND, THE INSURANCE COMPANIES HIRED MEMBERS OF THE IDSA TO WRITE THE TREATMENT STANDARDS FOR LYME WHICH THEY THEN ADOPTED. THIS IS HOW THE FILM "UNDER OUR SKIN" EXPLAINS THIS ISSUE.

[illegible] WESTERN BLOT HAS MANY PROBLEMS

~~WHOSE~~ COMMUNITY?

~~THE~~ ILADS ALSO HAS "EVIDENCE BASED GUIDELINES"
THE EVIDENCE WAS SUBMITTED TO THE IDSA THIS SUMMER
MY NEUROLOGIST HAS DIAGNOSTIC PROOF OF MY IMPROVEMENTS

THE WESTERN BLOT STUDY THAT THE IDSA DID WAS BASED ON A EUROPEAN VERSION.

* ELISA IS <u>NOT</u> A DIAGNOSTIC TEST, IT <u>DOES NOT</u> MEET THE STANDARDS OF A DIAGNOSTIC TEST.

I WAS HEALTHY AND VERY ACTIVE. I RODE MY MOUNTAIN BIKE 30 MILES PER weekend. SIX MONTHS LATER, I COULD BARELY WALK. BOTH LEGS WENT COMPLETELY NUMB AND I COULD NOT STAND.

EMOTIONAL RAGES
SLEEP ATTACKS VERY SIMILAR TO NARCOLEPSY
EXTREME PAIN
SLEEP APNEA
HEART ATTACK
JOINT PAIN
MEMORY LOSS, ...
INVOLUNTARY MOVEMENTS
GASTROPARESIS (
VISION
HYPERACUSIS (VERY SENSITIVE HEARING)

UNABLE TO RETRIEVE WORDS (INCLUDING MY CHILDRENS NAMES)
INABILITY TO CONCENTRATE
SEVERELY DEPRESSED IMMUNE SYSTEM
HYPOTHYROIDISM
EXTREMELY LOW TESTOSTERONE LEVELS
MUSCLE WASTING
FEVERS/SWEATS
HIGH PULSE RATE
INSOMNIA
DELAYED PHASE SLEEP SYNDROME
ADHD
UNSTEADY GAIT
LOSS OF BALANCE

I'VE HAD TO MAKE DECISIONS OF

COMPLAINT OF ANOTHER DOCTOR.

THE SIDE EFFECTS OF LYME ARE DEATH, LOSS OF COORDINATION

Article published on September 24, 2006

For many, it's the last refuge

Epping doctor's controversial practice takes a different look at Lyme disease

By MARGOT SANGER-KATZ
Monitor staff

September 24, 2006

Memory loss, confusion, poor coordination and sore knees. Hand pain, double vision, throat paralysis and falling. Involuntary movement, sensitivity to noise, stomach cramps and intense fatigue. These are the symptoms that Dr. Don McNeel's patients come to his office describing.

Some have complaints that are mostly arthritic: creaky knees and stiff hands. But most have more complex and troubling maladies. Some are in wheelchairs because of weakness. Others have cognitive problems that make them unable to work or care for their children.

What all of these patients share is a single diagnosis: Lyme disease.

"The patients are complicated, and their histories are multifaceted, and each treatment has to be tailored to the individual patient," said McNeel, who hung up his shingle in Epping as a Lyme disease specialist in November 2005.

LORI DUFF / Monitor staff
Jon and Carol Golublewski rest in their home in Bradford.
Zoom
Purchase Photos Online

McNeel believes that the subtle, multifarious nature of chronic Lyme disease demands specialists like him, who are well versed in the illness's tricky progression. But many in the infectious disease community say the reason why McNeel's patients are so varied and difficult to treat is because many don't really have the disease.

Lyme disease experts are divided into roughly two camps, and the sides view each other with disdain. The more conventional, conservative camp, which includes many of the physicians who first discovered and studied the disease in the 1970s, says Lyme is an easily cured bacterial infection that can cause long-term complications in a very small minority of patients. The other, McNeel included, contends the disease is a clever organism that often outlasts conventional treatment and requires vigorous, extended antibiotic therapy to cure chronically afflicted patients.

This battle is fought out less in academic journals and more often before state medical boards, where many Lyme specialists have had their medical licenses threatened, and on newspaper op-ed pages, where advocates offer withering attacks of their opponents' views. Each group says the other's definition of a Lyme diagnosis assumes its own results. The conservative doctors have a narrow definition of the disease, where most infections are easy to treat, the alternative practitioners say, so it's no surprise that they think simple treatment is all that's needed. And the alternative doctors diagnose everyone who walks through their doors, the conventional doctors say, so of course the treatment is complicated.

And then there are the patients, many of whom have been bounced from specialist to specialist because of their crippling symptoms. Often, they've received vague diagnoses - told they might be in the early, hard to detect stages of multiple sclerosis or Alzheimer's disease, that they have chronic fatigue syndrome or fibromyalgia -or told that their affliction is all in their head.

"One person sent me to another to another," said Cheryl Ann Victor, who's been seeing McNeel since February. When she first visited him, she'd experienced memory loss, fatigue, double vision, balance problems, arthritis and had difficulty concentrating. Her symptoms were so intense, she said, she lost her job as a computer programmer. "I went to see a rheumatologist who literally told me, 'You have rheumatoid arthritis, and all your other symptoms are due to your sleep disorder.' And I said, 'I don't have a sleep disorder.' And she said, 'Yes, you do.'"

'I'd be totally disabled'

For Jonathan Golubiewski, his symptoms started with a lingering flu. Every time he'd recover, it would come back. Then he started feeling tired all the time. He went to a sleep specialist, who treated him for sleep apnea, but his fatigue didn't get better. His back started hurting, but an MRI didn't show anything wrong with his spine.

Then his symptoms started getting weirder. He'd have numbness and tingling in his hands, or shooting pains. He'd lose strength in his legs and collapse, once while shopping in a drug store. And his stomach started bothering him. Last winter, he had what he calls his "downward spiral," when he visited the emergency room weekly in intense pain.

"They just kept testing and testing, and they couldn't find anything objective, they said," Golubiewski said.

After visiting the last neurologist, Golubiewski said, the specialist and his primary care doctor agreed that he "should really see a psychologist." That's when he and his wife turned to the internet, found out about Lyme disease, and first visited McNeel.

McNeel diagnosed Golubiewski with Lyme disease and started him on an aggressive course of IV antibiotic therapy. About a year later, Golubiewski still takes about 20 medications a day: two antibiotics to fight the infection, several herbal remedies to offset side effects from the antibiotics, antifungal medications, vitamin B-12 shots for his fatigue, painkillers and anti-inflammatories for his arthritis and sleeping pills to help him sleep through the night.

His mother has moved from New Jersey into his Bradford home to help him and his wife take care of their two kids. He was too exhausted to spend much time with them. And his wife, Carol, was kept busy doing her own work, fighting with the health insurance company and taking care of her ailing husband.

"Each day living with Lyme, it's like you have to decide which things you need to get done," she said.

During a recent visit, Golubiewski came to McNeel's office with Carol, who was a week away from delivering twins. As the couple sat opposite McNeel in his Epping office, Golubiewski reviewed his long list of medications and dosages, which he'd printed carefully on a piece of green paper.

Then McNeel sat back, put his hands on his desk and asked Golubiewski how he was doing. The patient started ticking through his recent symptoms. He still had trouble sleeping at night. He had severe fatigue when he was trying to work. He was extremely sensitive to loud noises and wore earplugs most of the day. He was experiencing regular stomach cramps. He thought he might be scraping his tongue against his teeth during involuntary movements. He sometimes experienced vertigo.

"Probably my major complaint right now would be the pain in my hands and my feet and my knees,"he said. "It's very painful."

But despite all of his continuing difficulties, Golubiewski said he was feeling much better from even his last visit a month earlier. After periods of short-term and long-term disability and a few months working part time and from home, he'd finally gone back to work full time the week before.

McNeel did a thorough physical exam, testing his patient's reflexes, feeling his glands and putting him through some neurological and physical tests. Then they got to talking.

"We don't know, because everyone's different, the long-term effects of having this serious long-term Lyme disease," McNeel said to the Golubiewskis. "It's been almost a year. I see a tremendous improvement, but when we're sitting here talking about symptoms, I feel like -are we getting anywhere?"

For the Golubiewskis, there's no question that the treatment has made a difference. They just wish that more doctors were "Lyme literate" so that Jonathan Golubiewski could have been diagnosed sooner.

"I could be dead," he said. "I'd be totally disabled. I was totally disabled in January."

'They're not crazy'

Dr. Don McNeel came to medicine by way of the clergy. The Epping physician has bachelor's and master's degrees in theology from Bob Jones University in South Carolina and was working as a youth pastor when he realized that he really wanted to be a doctor. He completed his pre-med courses at night and applied to the University of South Carolina School of Medicine as soon as he could.

His background, he said, gives him a particular perspective on the relationship between doctor and patient. He wants his patients to be treated like humans, he feels they need support as much as medicine, and he believes that hope will help them to heal.

That grounding serves him well in his current vocation. His patients are often very sick, very complicated and very discouraged. Typically, they come to him only after a half-dozen doctors have looked them over and found no cause for their suffering. And

"IS THERE ANOTHER ILLNESS THAT WOULD REQUIRE A LAW LIKE THIS?"

NOT FORESEEABLE.

~~THE OVER BY~~ [illegible] THIS IS A UNIQUE SITUATION BECAUSE OF THE IDSA'S [illegible] INTRUSION INTO ~~THE~~ OF MEDICAL COMMUNITY.

WESTERN BLOT

PROVIDES A GREYSCALE i.e. A SHADE OF GRAY THAT IS INTERPRETED SUBJECTIVELY BY A HUMAN.

WEIGHTS

[illegible]

[illegible] I TESTED [illegible] NEGATIVE ON THE WESTERN BLOT. THE FIRST TIME BECAUSE OF THE INTERPRETATION OF ONE BAND ON MY WESTERN BLOT.

EVIDENCE

KEYWORDS: SEVERAL MONTHS

EASILY DIAGNOSED

EASILY TREATED - GOV'T TEST LYME IN BIOTERROR LABS.

SPECULATION THAT LYME MAY CAUSE ALZHEIMERS, they often take many months of treatment before their disease improves.

"Patients need to know that they're not crazy, that their symptoms are real, that their diagnosis is real, and that there is hope," he said.

When McNeel talks to a patient, his manner is calm and confident. He draws clear diagrams that show how antibody tests work and how the spiral shaped Lyme bacteria can hide in body tissues. He listens carefully to their history and answers their questions respectfully. The monthly follow-up appointments he requires of all his patients typically run 45 minutes. The average primary care visit is closer to 15. (Because he doesn't accept health insurance, patients must pay $210 out of pocket for each of these visits.)

He's also upfront about the fact that many doctors won't agree with his diagnosis or his course of treatment. When he sees new patients, he typically slots more than two hours of time in order to take a history, do a detailed exam and talk to the patient about the treatment options and the controversy about Lyme disease.

During a recent visit, he spoke with Roxanne Zaharhuk of Westminster, Mass., whose sister, Becky Tinkham, had brought her in for a consultation. Zaharuk's short term memory had been eroding over the past two years. She'd visited a number of neurologists, including one at Massachusetts General Hospital who'd done a brain scan and determined that Zaharhuk might have early Alzheimer's disease, but that the pattern of atrophy in her brain was not typical for the disease.

"I'm not ready to accept Alzheimer's as the final diagnosis,"Tinkham said. "I just think that if there's a chance she has Lyme and could get better, we should find out."

After McNeel had done his workup, he told the sisters he recommended testing for Lyme and a few blood indicators that might help him make a diagnosis. Then he began his spiel on the "two standards of care" for Lyme disease.

McNeel took out a piece of paper, and he began writing down acronyms: CDC, NIH, IDSA, ILADS. The first three are the federal Centers for Disease Control and Prevention, the National Institutes of Health and the Infectious Diseases Society of America. All three of these groups describe Lyme disease as a simple bacterial infection that can be detected with blood tests and is killed by a two- to four-week course of antibiotics. ILADS is the International Lyme and Associated Diseases Society, a group of doctors who, like McNeel, believe that Lyme disease can be much more difficult to detect and often requires much longer and more aggressive courses of treatment. McNeel, like many ILADS doctors, recommends continuing antibiotic treatment until patients have been symptom-free for four to eight weeks.

"You need to understand with two eyes open going into this that I'm doing something that a lot of doctors aren't going to agree with,"McNeel said. "Let's talk about why its so controversial."

Then he pulled out three consent forms. One was a reprint of a letter from Dr. Gary Wormser, who wrote the treatment guidelines for the disease for the IDSA.

"Too often, patients with mysterious symptoms are misdiagnosed with Lyme disease. Often they are prescribed prolonged antibiotic treatment, an unnecessary and potentially harmful approach," The letter reads.

"Although patients sometimes report feeling better after taking a drug, that does not necessarily prove cause and effect. In one clinical trial of long-term treatment of Lyme disease, almost 40 percent of patients given a placebo felt much better," it continues.

At the bottom of the page is the statement: "I have read this article and understand the controversy, but choose to follow the ILADS guidelines."

Zaharhuk signed the consent forms.

'They haven't proventheir case'

McNeel is careful about consent forms, in part because he's learned from the legal battles of other ILADS doctors. Several have had their work challenged by state medical boards and some have had their licenses suspended. Most medical boards consider it to be professional misconduct for a doctor to practice outside of an "accepted standard of care."

In the case of Lyme disease, the IDSA doctors say that their treatment guidelines are the standard. But the ILADS doctors say that there are actually two standards of care - theirs and the treatment recommended by their opponents. Which doctors are chosen to testify before the board can have a big influence on what they decide.

"You do have the infectious disease view, which is that two weeks of antibiotics cures everybody,"said Raphael Stricker, the president of ILADS and a hematologist who sees a lot of Lyme disease patients in his practice. "And the reason for that is they don't treat any of these patients."

Dr. Jonathan Edlow, a Harvard Medical School professor whose book Bull's Eye chronicles the history of Lyme disease, said the case is complicated because the ILADS doctors, whom he calls "alternative,"haven't done enough research to prove their theories right or wrong.

"Part of the difficulty with the alternative camp is that they haven't collected cases and gone about it in a scientific way," he said. "That doesn't mean they aren't right; it just means that they haven't proven their case."

Most infectious disease doctors say the two- to four-week course of antibiotics kills all the bacteria, and that any lingering symptoms won't be helped by further treatment. They warn about the risks associated with long-term antibiotic use, which can include allergic reactions and kidney and liver damage. They also say that overuse could encourage the growth of antibiotic-resistant bacteria.

The groups also differ on how to diagnose the disease. ILADS doctors believe conventional blood tests for the disease often come back negative, even when people are infected. McNeel said he considers Lyme disease to be a "clinical diagnosis," based on both symptoms and blood tests.

But infectious disease expertssay blood tests are reliable 95 percent of the time and sometimes even come up positive when the patient isn't sick. A doctor treating a patient with ambiguous symptoms and a negative blood test for chronic Lyme disease may miss the patient's real diagnosis, they say.

"As a former clinician, you want to do what you think helps your patients, but the other side of it is you don't want to be randomly experimenting on your patients, either," said Kevin Griffith, a medical epidemiologist at CDC who researches Lyme disease. "If you're not sure what you're treating, antibiotics are not just benign things you give to people. You have to balance the benefits of what you're doing with the possible risks."

Will believers be vindicated?

When he talks about his work, McNeel doesn't skirt the controversy. He discusses it with every patient he sees. And he's reminded of it every time he interacts with an outside medical organization. Many primary care doctors won't support his treatment of their patients, he said. Most insurance companies won't cover his services. (He bills his patients directly.) Exeter Hospital won't let him admit patients without getting a consultation from an infectious disease specialist, he said. When he was doing family practice, he was able to admit any patient he wanted.

But the debate, while frustrating, hasn't shaken his confidence that he's offering his very sick patients the best treatment available.

"I've been called a quack by several doctors and been labeled as overly aggressive," McNeel said. "And you get to the point where, bottom line is, what can I do to help these patients get better?"

And while he has doubts about how much he's helping individual patients and feels terribly when they're not improving at the pace he'd like, he still believes that the ILADS treatment will be vindicated over time. It will take more research, he said, and more cases to show how the treatment helps the patients. Since he's opened the practice, he's seen patients come to the end of their treatment and go back to their normal lives, he said. And he's heard from his mentors that he'll see that more and more often. Stricker said 70 to 80 percent of his patients recover.

Lyme disease, McNeel said, is like stomach ulcers were 50 years ago. The medical consensus then was that if you were sick, it was because of a poor diet or stress. But it turned out the ulcers were caused by an easily treated bacterial infection. The doctors who discovered the true cause of ulcers got no respect at first, McNeel said. When Barry Marshall first presented his findings to colleagues, McNeel said, "he was laughed out of the meeting."

"Everyone said, 'You're crazy.'And last year, he won the Nobel Prize."

(Margot Sanger-Katz can be reached at 224-5301, ext. 307, or by e-mail at msanger-katz@cmonitor.com.)

—— End of article

By MARGOT SANGER-KATZ

Monitor staff

This article is: 1222 days old.

1-28-2010

HB 1326
File

Lyme Testimony: Arlene Stoppe 85 Leavitt Hill Rd, Ashland, NH 603-968-4478

- **1980** I saw 4 doctors at 3 different hospitals, no diagnosis, all in NH
- **2002** 6 months of testing at Mass General, no diagnosis ELISA Negative
- **June of 2009** My symptoms got worse. August 2009 ELISA Negative
- **DIAGNOSED** Sept 2nd, 2009 with Chronic Lyme Disease, Western Blot test
- **SYMPTOMS:**
  - ***Chronic Fatigue (sleep 16-20 hours a day for 2 ½ months straight)***
  - ***Joint pain***
  - ***Muscle pain***
  - ***Pain in my head and throughout my body***
  - ***Balance problems***
  - ***Motor control problems***, numbness
  - ***Concentration problems***, sleeplessness, can't multitask
  - ***Memory Lapses & other issues as well***

- **EXERCISE** scaled way back.
- **WORK SCHEDULE** went from 50-60 hours a week down to 15 hours a week
- Lucky for me – **I work for myself** so I don't plan on firing me any time soon. Others are not so lucky.
- **RESEARCHING** since September.
- **LONG TERM ANTIBIOTICS WORK.** Currently almost 5 months into long term antibiotic treatment.
- Insurance companies **LODGING COMPLAINTS** against Doctor's that treat Lyme patients.
- Doctors have **moved out of state or stopped treating Lyme patients.**
- My **INSURANCE COMPANY** contacted me in Oct 2009 to set up this 24/7 access to **NURSES**.
- They are **NOT LYME LITERATE**, do not even know the terminology. I have to teach them about Lyme disease. Babesia
- Every month my insurance company is **DOCUMENTING:** via their 'Nurses'.
  - ***Medications***
  - ***Vitamins***
  - ***Symptoms***
  - ***Work habits***
  - ***Exercise***
  - ***State of my Mental Health***
  - ***Religious views***
  - ***Attitude & outlook***

- I believe their purpose is not to help me but to **BUILD A CASE** against my doctor. and/or suspend my insurance coverage for treatment.
- The insurance company never contacted me when I had 5 years of **ALERGY SHOTS**. 2005-2009
- This is **SHAMEFUL** of the insurance companies. It's all **ABOUT MONEY**, not treating patients.
- Insurance companies are **NOT FIT** to dictate patients' treatments.
- Should not be allowed to **LODGE COMPLAINTS** against doctors.
- This **NEEDS TO STOP.**
- **I ASK FOR YOU TO SUPPORT THIS BILL**. So the doctors can treat Lyme patients and patients can get the treatments they desperately need.

A..

File HB1326

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 what was making her sick. Despite being a well-read, cutting-edge emergency room physician she had spent years of going from doctor to doctor to get answers. It was her own self-perseverance that pushed her to find out what was really wrong because she knew it could not be "all in her head." The pains she felt were real. The symptoms she had, she felt sure, were being caused by an illness. In her research she discovered the controversy surrounding Lyme Disease and this opened her eyes to what could be wrong. She was tested and now is being treated for both Lyme Disease and Ehrlichiosis. She's gone misdiagnosed for over 20 years.

In her plight to discover her own ailment she started to feel concerned about me. Over the years I had shared various health problems that I had with her. These problems, I had always been led to believe by doctors, were no big deal or just a part me. Given my medical history and the fact that I had found a deer tick on myself when I was younger, she thought better of that determination.

in and of itself is not a easy process ey LLMD, try to remain anonymous out of fear

She urged me to get to a "Lyme Literate Medical Doctor" and this process ~~began to open doors to this~~ new secret world. Just to find a "lyme-literate doctor," I had to ~~contact a local~~ support group facilitator who explained of the persecution of doctors who were willing to treat, the ignorance of doctors who refused to believe Lyme Disease could be chronic, and the frightening lack of understanding surrounding the disease by the majority of the medical world.

/

I found a Lyme Literate doctor and he concurred with my sister's assessment. He tested me for Lyme Disease and that test came back positive (even in accordance of a CDC positive test).

The most frustrating part is that I went to my PCP at Portsmouth Hospital the day I found the tick on myself and brought it with me. I asked them to test it, but they would not. I was dismissed because I did not have the "tell-tale" bull's eye rash. As weeks went on and symptoms started to present, I was continually told that without the rash, it was not Lyme Disease.

It was the 105 fever five weeks later that landed me in the hospital combined with the finally-present faint rash that had them admit, this *could* be Lyme. I was treated with ten days of doxycycline and **thought** I was cured. Only years later would I come to find out how ineffective this treatment was.

~~So started the beginning of the long road ahead.~~ After going misdiagnosed for 16 years I was finally validated by an amazing Lyme doctor who knew what was wrong with me and how to get me well.

the myriad of symptoms I had been ~~[illegible]~~ experiencing were

I now realized ~~that~~ the floaters in my eyes, extreme light sensitivity, drenching night sweats, fits of hypoglycemia, a five month gap of disabling insomnia that could not be touched by any prescription sleeping medications, ringing in my ears, heartburn, headaches, crippling anxiety, panic attacks, depression that would come on despite me having a good life, ulcerative colitis, sporadic pain in my glands, nausea, and stomach upset were not just a part of who I am. They were caused by chronic infection. More specifically, as time and experienced doctors have come to find out, Lyme disease plus two other tick-borne infections – Bartonella and Babesia.

fevers, word searching problems

I've been in treatment for 14 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 one and this was no easy task.

I drive five hours each way to see my Lyme doctor. 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. ~~And this is just the start of a long-term treatment plan given the length of my illness.~~

The time commitment and financial burden I have felt from this illness is truly staggering. ~~Despite all the~~ struggles and frustrations, ~~I don't look b~~ack as ~~no good can come of that. I look forward and~~ 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.

HB 1326

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.

The injustice that surrounds this disease is criminal. None of us who are sick should have to fear not being taken seriously by the majority of the medical community or fear being denied treatment because of our insurance companies don't want to pay. ~~This is~~ a dis~~grace as~~ we deserve treatment just like a patient who has cancer, heart disease, or any other complicated disease.

Despite what we're led to believe, Lyme Disease **is** common. It masquerades as many different illnesses and is a highly political, controversial disease. It is **not** easily treatable (unless caught in the early stages) and in its chronic form may not even be curable. A whole new world has been shown to me and the more I share my story, the more people I find who are also sick or know someone who is. It is endemic in many areas of New Hampshire and anyone who steps foot outside is at risk. If we don't have doctors who are educated about how serious this is and/or who are willing to treat both early stage and chronic Lyme with long-term antibiotic treatment, it will be just a matter of time before the majority of us will have one or more tick-born infections.

In all these years, despite my challenges, I have never stopped working and as an adult have always supported myself. I don't ask my government for much ~~and by nature am opposed to handouts.~~ but Now, however, is a time that I must ask for you **to support our doctors**. We have so few Lyme literate doctors. Of the ones we do have they put their livelihood on the line by treating those of us who are suffering. They do so knowing full well that they put themselves at risk, but they also know it's the right thing to do and that no one should have to suffer.

These doctors should be protected and commended as they are the true heroes in this convoluted story of what is Lyme Disease. 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 581, Sunapee, NH 03782

File
HB1326

January 20, 2010

Health, Human Services and Elderly Affairs Committee

To Whom It May Concern,

On august 18, 2009 after 6 years of improper diagnosis and treatments I was finally properly diagnosed with Lymes Disease. This letter is an account of what; I and other sufferers of this disease must endure. I have be and continue to deal with the many road blocks that hinder physicians from properly diagnosing and treating this disease. After reading this account, I hope you will consider making whatever changes necessary to remove those roadblocks both legal and medical so that we can receive the treatment that we deserve.

I am continuing to hold down my job for insurance purposes. Physically it has been almost impossible to keep on working. I have always worked. First job 16 years old and have always worked since then. I am the sole supporter of my family. I am now 43 years old.

After doing my own research, I suspected that I might have Lymes disease. I had a telltale bug bite on my arm and had shown doctors the bite numerous times. It still itches till this day. Below are some of the symptoms that I have had to live with.

a) Chronic Fatigue that was always blamed on my thyroid. Massive fatigue for the last 6 years. Continuous respiratory ailments – Bronchitis, phnemonia

b) Migraine Headaches

c) Joint and shoulder pains that unbearable. Doctors could not find anything with x-rays. More or less made me feel like I was making it up. Could not sleep for a year and a half due to shoulder pains.

d) Cognitive Problems. These have been getting worse over the past 2 to 3 years. Short term memory.

e) Depression. I go through bouts of depression on a weekly basis.

f) Right hand and arm went numb. Doctor sent me for carpal tunnel test. Came back negative. She then wanted me to go to physical therapy 4 times a week. I travel for work and am out of town usually Monday through Thursday. I told her that I wanted to go to a neurologist. She told me that the physical therapist is good at diagnosing. I told her that I thought that was her job. Started to look for new doctor.

g) Both feet went numb up to mid thighs. Went to two neurologist both diagnosed it as Multiple Sclerosis. I even had information on Lymes and brought it to one of the neurologist appointments. She ran the Quest Lab Lymes test and it came back negative (this lab only has a 30% accuracy). She disregarded me. I then had to go through a spinal tap procedure, which is no fun. Then to top it off I had a spinal fluid leak from the spinal tap. I suffered for 4 day. I could not get up from a laying down position without having my head feel as if it was going to explode. I then had to return to the hospital to get a Blood Patch to stop the spinal fluid leak. After all this, I then had no choice but to start the M.S. medication Avonex. Avonex is a steriod that you inject into your muscles on a weekly basis. For 3 months I was on this medication. I had total body aches through my whole body. I laid in bed crying from the pain. First week on injections I only felt ill for 2 days. Every week after that it got longer. Finally went I stopped the Avonex. I was doing my injections on Thursday and feeling sick all the way to the following Thursday. The side effects of this drug were only suppose to last 24 hours after injection. More medical expenses that did nothing to help me. I also found out later that the worst thing you can put a lymes patient on is a steroid. Now I know why my body was rejecting the Avonex.

h) I finally found a primary doctor that would listen to me. I then found a LLMD and got the referral. The waiting period to see the doctor was 2 months. Finally got in to the doctor and had stopped the MS medication. The LLMD then requested some blood work from a lab out in California that is more accurate and more detailed than the lab that the insurance companies dictate to use. I had to pay out of pocket ($1000.00). I do have insurance. I am finding that the insurance companies only cover what will make them money. Not what will make their customers healthier. My LLMD has been treating me since August of 2009. I was undiagnosed and misdiagnosed for 6 years and now my LLMD has to walk lightly in fear of getting his license revoked. He could be prescribing two medications right now for me. One is an antibiotic and the other is not. He feels that these medications would do well for me but there is the issue of the state going after him. He can not prescribe these medications until the legislature protects him. These medications could be the difference of me getting better. They would help my fight against this disease. But then again the insurance companies will not pay for and will notify the state if my doctor prescribes these to me. What is a sick person with insurance to do in this wonderful country of the USA?

If my condition continues to deteriorate due to a disease that is curable if caught early or treatable if the law allowed, I will be forced to seek some form of disability. Due to my inability to hold a job.

Please help.

Sincerely,

Julie Sanders

37 Gamache Street

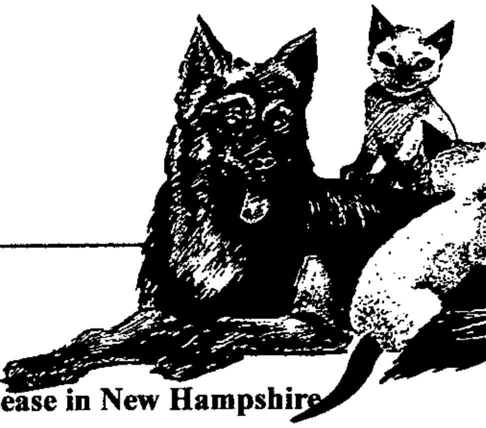
Manchester, NH 03102

File
HB 1326

apple tree
ANIMAL HOSPITAL

ROBERT T. FURNESS D.V.M.

MAPLE STREET (Exit 6, I-89) — CONTOOCOOK, NEW HAMPSHIRE 03229 — TELEPHONE (603) 746-5050



A Veterinarian's perspective on Lyme disease in New Hampshire

Lyme disease (Borreliosis) is caused by the spirochete Borrelia burgdorferi transmitted by the deer tick Ixodes scapularis. It is different than most diseases in that it spreads through the connective tissue in the body as compared to most diseases that travel through the blood vessels. This means that any antibiotics have to leave the blood vessels and get into the connective tissue to be effective. This usually requires higher doses and longer duration to be effective.

Veterinarians have the advantage over Physicians in that we have a rapid antigen test that can readily detect Lyme disease in our patients. About six years ago, Apple Tree Animal Hospital began using this test. At that time we found about 20% of the dogs tested were positive for antigen to Lyme disease. At that time we were surprised by the number as this is New Hampshire, not Lyme Connecticut. Not all of these dogs were presenting with any clinical signs. Today this number would not surprise us. If it were not for a canine Lyme vaccine, I am sure the number would be greater.

In 2005 the University of New Hampshire collected deer ticks in the fall and found 36% of the Ixodes ticks were infected with Borrelia. This was repeated in 2007 and had risen to 53%. In 2008 the total was now 62%. Lyme disease is here in New Hampshire.

It seems only logical that since ticks bite both dogs and humans, and we both traverse the same landscape, if Lyme disease is increasing in dogs it must also be increasing in humans.

Due to the possible severity of the disease left untreated, or not treated sufficiently, it seems prudent to err on the side of acting presumptively rather than doing nothing. I treat antigen positive dogs with Doxycycline even if they are not showing clinical signs.

It should not be a crime to treat humans in a similar fashion if it has the potential to relieve future pain and suffering. Medical Doctors should be the ones to make this decision without fear of legal retribution.

Respectfully,

Robert T. Furness, D.V.M.

48 Positive Lyme
Last year -
However MOST
of our dogs are protected
with LymeVAX and
tick prevention (Frontline
These are animals who
Chose NOT to use those
options!

Apple Tree Animal Hospital
WHOGOT REPORT

Patient 25 Lyme ⊕	Doctor	Qty	Date	Species	Breed	Age	Sex
Gretta ⊕	Robert T. Furness, DVM	56	05-28-09	CANINE	German Shepherd	7y	F
Peanut ⊕	Robert T. Furness, DVM	60	01-05-10	CANINE	Boxer	5y	S
Peanut	Robert T. Furness, DVM	28	12-11-09	CANINE	Boxer	5y	S
Khaki ⊕	Robert T. Furness, DVM	28	05-04-09	CANINE	Anatolian Shepherd	2y	S
Kayla ⊕	Robert T. Furness, DVM	28	11-10-09	CANINE	Siberian Husky	21m	F
Brady ⊕	Robert T. Furness, DVM	56	09-08-09	CANINE	Retriever, Labrador	7y	N
Taj	Robert T. Furness, DVM	28	05-04-09	CANINE	Retriever, Golden	12y	N
Taj	Robert T. Furness, DVM	56	01-18-10	CANINE	Retriever, Golden	12y	N
Taj	Robert T. Furness, DVM	4	05-19-09	CANINE	Retriever, Golden	12y	N
Bodie ⊕	Robert T. Furness, DVM	56	05-16-09	CANINE	Mix,Great Pyrenese	4y	N
Cobalt ⊕	Robert T. Furness, DVM	28	06-17-09	CANINE	Australian Shepherd Mi	3y	S
Vanity ⊕	Robert T. Furness, DVM	28	04-07-09	CANINE	Eurasier Mix	2y	S
Haley	Robert T. Furness, DVM	28	08-15-09	CANINE	Retriever, Labrador	7y	S
Daisy ⊕	Robert T. Furness, DVM	56	12-01-09	CANINE	Great Dane	7m	F
Brook ⊕	Robert T. Furness, DVM	28	01-18-10	CANINE	Terrier, Boston	5y	S
Miranda ⊕	Robert T. Furness, DVM	56	01-14-10	CANINE	Retriever, Labrador	10y	S
Miney	Robert T. Furness, DVM	5	07-21-09	CANINE	Chihuahua	2y	F
Pierre	Robert T. Furness, DVM	14	05-12-09	CANINE	Papillon	9y	N
Chance ⊕	Robert T. Furness, DVM	28	05-28-09	CANINE	Mix, Lab. Retriever	7y	N
Boomer ⊕ Ehrliccia	Robert T. Furness, DVM	28	03-27-09	CANINE	Mix, Husky	11y	N
Alex ⊕	Robert T. Furness, DVM	28	11-24-09	CANINE	Mix, Lab. Retriever	5y	N
Abby ⊕	Robert T. Furness, DVM	28	09-22-09	CANINE	Terrier, Soft Wheat.	11y	S
Large Marge ⊕	Robert T. Furness, DVM	28	05-04-09	CANINE	Akita	6y	S
Large Marge	Robert T. Furness, DVM	28	05-21-09	CANINE	Akita	6y	S
Max ⊕	Robert T. Furness, DVM	56	07-28-09	CANINE	Retriever, Labrador Mi	8y	N
Sheiba ⊕	Robert T. Furness, DVM	28	06-20-09	CANINE	German Shepherd	4y	F
Nos	Robert T. Furness, DVM	56	04-08-09	CANINE	German Shepard	19m	M
Miscellaneous / Puppi	Robert T. Furness, DVM	56	06-05-09	CANINE	German Shepherd		F
Mica ⊕	Robert T. Furness, DVM	28	09-04-09	CANINE	Retriever, Labrador	12y	S
Missy T ⊕	Robert T. Furness, DVM	28	05-01-09	CANINE	Collie, Rough Coat	6y	F
Missy T	Robert T. Furness, DVM	28	08-04-09	CANINE	Collie, Rough Coat	6y	F
Abby ⊕	Robert T. Furness, DVM	28	05-13-09	CANINE	Mix, Beagle	2y	S
Murphy ⊕	Robert T. Furness, DVM	28	05-02-09	CANINE	Retriever, Labrador	3y	N
Bella ⊕	Robert T. Furness, DVM	28	04-06-09	CANINE	Pointer,German Short	3y	S
Ginger ⊕	Robert T. Furness, DVM	56	12-26-09	CANINE	Retriever, Labrador	23m	F
Tonka	Robert T. Furness, DVM	120	12-01-09	CANINE	Retriever, Labrador	2y	M
Annie ⊕	Robert T. Furness, DVM	28	09-17-09	CANINE	Retriever, Golden	16m	S
Quarry ⊕	Robert T. Furness, DVM	28	01-18-10	CANINE	Collie, Rough Coat	2y	M
Drew ⊕	Robert T. Furness, DVM	28	04-13-09	CANINE	Retriever, Golden	14y	N
Daro ⊕	Robert T. Furness, DVM	28	07-01-09	CANINE	German Shepard	4y	M
Chico	Robert T. Furness, DVM	30	10-22-09	FELINE	Domestic Short Hair	14y	N
Chico	Robert T. Furness, DVM	30	07-15-09	FELINE	Domestic Short Hair	14y	N
Chico	Robert T. Furness, DVM	30	04-07-09	FELINE	Domestic Short Hair	14y	N
Luke ⊕	Robert T. Furness, DVM	56	03-27-09	CANINE	Retriever, Golden	4y	M

Patient 20	Doctor	Qty	Date	Species	Breed	Age	Sex
9 September 2009	Robert T. Furness, DVM	28	12-30-09	(ALL)		14m	
9 September 2009	Robert T. Furness, DVM	15	01-14-10	(ALL)		14m	
Samson ⊕	Robert T. Furness, DVM	56	08-15-09	CANINE	Retriever, Labrador	5y	N
Snickers ⊕	Robert T. Furness, DVM	56	12-10-09	CANINE	Mix, German Shepherd	20m	S
Frostfire ⊕	Robert T. Furness, DVM	56	10-09-09	CANINE	Retriever, Golden	12y	M
Hallie	Robert T. Furness, DVM	28	12-11-09	CANINE	Retriever, Labrador	8y	S
Hallie ⊕	Robert T. Furness, DVM	28	11-13-09	CANINE	Retriever, Labrador	8y	S
Jasmine ⊕	Robert T. Furness, DVM	28	04-07-09	CANINE	Mix, Lab. Retriever	13y	S
Missy	Robert T. Furness, DVM	14	04-25-09	CANINE	Retriever, Labrador Mi	15m	S
Missy	Robert T. Furness, DVM	28	05-12-09	CANINE	Retriever, Labrador Mi	15m	S
Lucy ⊕	Robert T. Furness, DVM	28	08-29-09	CANINE	Retriever, Labrador	6y	S
Max ⊕	Robert T. Furness, DVM	56	03-28-09	CANINE	Mix, Gold. Retriever	6y	N
Sophie ⊕	Robert T. Furness, DVM	28	04-27-09	CANINE	Mix, Lab. Retriever	21m	S
Toby ⊕	Robert T. Furness, DVM	56	04-27-09	CANINE	Retriever, Labrador	6y	N
Zoe ⊕	Robert T. Furness, DVM	28	06-03-09	CANINE	Poodle,Standard	9y	S
Sox ⊕	Robert T. Furness, DVM	56	05-12-09	CANINE	Mix, Lab. Retriever Mi	15y	S
PJ ⊕	Robert T. Furness, DVM	28	04-11-09	CANINE	Retriever, Labrador	18m	M
Rudy ⊕	Robert T. Furness, DVM	28	09-03-09	CANINE	Terrier,Jack Russell	14y	N
Zion ⊕	Robert T. Furness, DVM	56	05-15-09	CANINE	Retriever, Labrador	8y	N
Zion	Robert T. Furness, DVM	56	04-09-09	CANINE	Retriever, Labrador	8y	N
Max ⊕	Robert T. Furness, DVM	28	04-29-09	CANINE	Retriever, Labrador	10y	N
Bayla ⊕	Robert T. Furness, DVM	28	05-15-09	CANINE	Retriever, Golden	2y	S
Irving	Robert T. Furness, DVM	5	06-09-09	FELINE	DSH Domestic Shorthai	10y	N
Buddy ⊕	Robert T. Furness, DVM	28	02-25-09	CANINE	Welsh Corgi Pembroke	18m	N
Bear ⊕	Robert T. Furness, DVM	28	11-12-09	CANINE	Mix, German Shepherd	3y	N
Max ⊕	Robert T. Furness, DVM	56	07-21-09	CANINE	Mix, Lab. Retriever	8y	M
Rebecca ⊕	Robert T. Furness, DVM	28	04-27-09	CANINE	Shetland Sheepdog	7y	S

ROBERT J. ANDELMAN, M.D.
President

AMY FEITELSON, M.D.
Vice President

PENNY TAYLOR
Administrator

1776

ROBERT P. CERVENKA, M.D.
ROBERT M. VIDAVER, M.D.
LOUIS E. ROSENTHALL, M.D.
NICK P. PERENCEVICH, M.D.
MARK SULLIVAN, P.A.
BRIAN T. STERN, PUBLIC MEMBER
GAIL A. BARBA, PUBLIC MEMBER
DANIEL MORRISSEY, O.P., PUBLIC MEMBER

New Hampshire Board of Medicine

2 INDUSTRIAL PARK DRIVE, SUITE 8, CONCORD, NH 03301-8520
Tel. (603) 271-1203 Fax (603) 271-6702
TDD Access: Relay NH 1-800-735-2964
WEB SITE: www.nh.gov/medicine

February 8, 2010

Representative Cindy Rosenwald
Chairman
House Health, Human Services and
Elderly Affairs Committee
State House Annex
Concord, NH 03301

Dear Representative Rosenwald:

The Board of Medicine ("Board") at its February 3, 2010 meeting voted to approve the following position regarding House Bill 1326, "AN ACT relative to the use of long-term antibiotics for the treatment of Lyme disease."

HB 1326 currently states in part: "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."

The Board respectfully opposes HB 1326 for the following reasons:

1. No other disease, therapy, or mode of treatment has statutory protection from oversight by the Board.
2. The Board sees this precedent as dangerous: will other therapies or treatments be similarly exempt from oversight and regulation by the Board?
3. The Legislature has traditionally left the practice of medicine to physicians and the oversight of physicians to the Board. 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 surgery?
4. If a physician violates standards or practices unsafely, he/she is subject not only to the Board but to our tort system and patients may seek redress through the Courts.

5. At present, there has never been a case before the Board involving use of long-term antibiotic therapy for treatment of chronic Lyme disease.
6. Because physicians are free to prescribe within the limits of safe practice, and because the Board has yet to address this issue via a complaint, suit, or claim, it takes no position and has no prejudice regarding the merits of such treatment.

For the above reasons, the Board respectfully opposes the passage of HB 1326.

Sincerely yours,

Robert J. Andelman, MD/pt

Robert J. Andelman M.D.
President
NH Board of Medicine

RJA/pt

California Lyme Disease Association

1026 Mangrove Ave #10 ◆ Chico CA 95926 ◆ 707-489-5320 ◆ pmerv@hughes.net

January 20, 2010

The Honorable Cindy Rosenwald
Chairwomen
Health, Human Services and Elderly Affairs Committee
New Hampshire House of Representatives

Dear Chairwomen Rosenwald:

I am writing to express CALDA's support for New Hampshire House Bill 1326, an act relative to the use of long-term antibiotics for the treatment of Lyme disease, which provides protection to doctors who do not comply with Lyme disease treatment guidelines developed by the Infectious Diseases Society of America (IDSA). Please enter this letter into the public record as written testimony.

The IDSA Lyme treatment guidelines are highly restrictive, ineffective, and leave seriously ill patients who are not cured under the guidelines without any additional treatment options. The IDSA panel which developed the guidelines had serious and significant commercial conflicts of interest with vaccine manufacturers, Lyme diagnostic kit distributors, and insurance companies. The interests of patients and their treating physicians were not represented on the panel, with the result that commercial interests were placed above quality patient care.

The conflicts were so egregious that Connecticut Attorney General Richard Blumenthal launched an antitrust investigation into the IDSA guideline development process. In May 2008, the AG announced a settlement with the IDSA. In a scathing indictment of the process, he concluded that important procedural safeguards were lacking:

- Several of the most powerful panelists held undisclosed financial interests;
- IDSA failed to follow its own procedures for appointing the panel chair and members;
- The panel refused to accept or meaningfully consider information regarding the existence of chronic Lyme disease and blocked appointment of scientists and physicians with divergent views on chronic Lyme.

Under pressure of the investigation, the IDSA entered into an antitrust settlement agreement with the Attorney General. The settlement agreement forced the IDSA to reconstitute a new panel free of conflicts of interest to re-evaluate its Guidelines in a public hearing held on July 30. The panel is expected to make a decision within a few months. The settlement requires the panel to consider scientific research the prior panel had ignored and to consider divergent viewpoints. We encourage you to view these presentations (which can be viewed at the IDSA website (www.idsociety.org) and review the scientific evidence submission of ILADS (www.ilads.org) which included approximately 300 pages of analysis and over 1300 pages of peer reviewed scientific evidence disputing the IDSA guidelines recommendations.

The guidelines severely restrict clinical judgment and deny patients access to treatment options. Despite the IDSA claims that its guidelines are "voluntary," medical boards, insurers, hospitals, schools and even child custody agencies regard them as mandatory and IDSA members enforce the guidelines in unprofessional conduct actions against physicians who fail to comply. Indeed, the IDSA uses the guidelines as a sword to drive its competitors from ILADS out of business for non-compliance.

The hardship caused to patients by these guidelines is severe. A CALDA survey of more than 3,600 people with Lyme disease found that the average patient waited over four years, seeing multiple doctors, before being diagnosed and one third waited more than six years to be properly diagnosed. In addition:

- **Only 13%** were *diagnosed using the IDSA-recommended two-tiered Lyme testing* approach. 20% were diagnosed by western blot using CDC criteria, and 42% were diagnosed clinically with supporting lab tests that did not use CDC surveillance criteria.
- **90%** had difficulty or extreme *difficulty finding a knowledgeable physician* to treat Lyme disease. 51% had traveled more than 100 miles to obtain treatment, and 53% had been forced to travel out of state to obtain care.
- **54%** had been treated and *failed treatment under IDSA protocols.* A resounding 81% stated that they would not consider being treated under IDSA protocols.
- **More than 60%** of respondents who failed to improve under IDSA *protocols improved with additional treatment.*
- **41%** of patients were *not able to afford the medical care* they needed.
- **88%** *had to cut back on work, school and household activities.* 50% had to either quit work or school due to illness, and another 11% went from full-time to part-time work or school.

Denying treatment to patients has huge public health implications. People with under-treated Lyme disease often lose their jobs and insurance. They go from being productive, tax-paying citizens to being disabled consumers of state-provided services, including disability benefits and special accommodations under Section 504 of the ADA. Children lose years of their childhood, missing important developmental milestones.

Physicians need protection so they can treat patients without fear of prosecution by state medical boards and recrimination from colleagues. Please pass legislation to ensure that physicians are allowed clinical discretion to treat – including antibiotic treatment for longer than 4 weeks if needed – according to their best judgment and evaluation of the individual patient. Please ensure that patients are allowed an informed choice of the treatment they prefer, based on their own personal values and situation.

Sincerely yours,

Phyllis Mervine, President

File Copy HB 1326

1776

State of New Hampshire

HOUSE OF REPRESENTATIVES

Rockingham District 6
East Road
Atkinson, NH 03811

February 1, 2010

RE: HB-1326 - Please help Lyme disease sufferers in Southern NH – Support OTP

Representative Cindy Rosenwald, Chair
House Health, Human Services and Elderly Affairs Committee
Room 205, Legislative Office Building
Concord, NH

Dear Chair Rosenwald and Committee:

I am asking you to support the passage of HB-1326 relative to the use of long-term antibiotics for the treatment of Lyme disease.

I represent the town of Atkinson, in Southern New Hampshire. Our town has been hit hard by Lyme disease. In some neighborhoods, over 50% of the homes have at least one person who has the disease. Lyme disease continues to move north, and soon your communities may be hit as hard as Atkinson.

My neighbors and friends in town need relief from their suffering. The traditional 4 week treatment is not curing the disease. They need long term help.

Please approve HB-1326, so that physicians can have the freedom and flexibility to help their patients win the battle with Lyme disease.

Respectfully,

James Michael Garrity

Rockingham District 6

File HB1326

My name is Pete Ballou and I am a truck driver from Brookline, NH. My experience is similar to almost every Lyme victim I have talked to or read about. I have been extensively tested by non-Lyme literate doctors but they refused to run a Western Blot test for Lyme disease -everything was negative or inconclusive. I have chronic Lyme disease symptoms but they denied that they are Lyme disease symptoms. I ended up getting tested outside of my medical system but the non-LLMDs still ignored the results. I don't trust these doctors anymore and if I had listened to them, I would be sitting at home right now, still undiagnosed. The Lyme literate doctor that I am seeing is the first one out of around fifteen doctors in the last two and a half years who is willing to help me. I'm very concerned that he won't be allowed to help me get my life back. I can't work or drive anymore and I'm unable to do anything that I used to enjoy including whitewater kayaking, iceboating, hiking, and skiing. Now, it's all I can do to go grocery shopping once a week with my wife. We need to protect Lyme literate doctors because they have the knowledge, skill, and courage to help us. Please read the book, *Cure Unknown,* by Paula Weintraub. It describes the problems that Lyme disease patients have to deal with trying to get adequate care and the controversy surrounding Lyme disease.

I am fully aware of the potential dangers of long-term antibiotic use but it's more dangerous to go undiagnosed and untreated by non-Lyme literate doctors. It is easier for farmers to give their livestock an endless supply of antibiotics than it is for Lyme literate doctors to treat their patients. Thousands of Lyme disease patients have been successfully treated with long term antibiotics. Many states have laws protecting Lyme literate doctors and some states mandate insurance coverage for long term antibiotic therapy.

We should not have to beg our doctors for referrals or be sent home undiagnosed by doctors who are not fully knowledgeable about Lyme disease. We cannot let non-Lyme literate doctors determine our medical treatment – we should join with Connecticut and other states and vote in legislation to protect our Lyme literate doctors. Please help Lyme disease patients in New Hampshire by supporting House Bill 1326. Thank you.

File Copy HB 1326

International Lyme and Associated Diseases Society

P.O. Box 341461 • Bethesda, Maryland 20827-1461

ILADS

www.ilads.org • E-mail: lymedocs@aol.com • 301-263-1080 • Fax: 301-263-0776

The Honorable Cindy Rosenwald
Committee on Health, Human Services & Elderly Affairs
New Hampshire House of Representatives
101 Wellington Street
Nashua, NH 03064-1616

The Honorable Gary Daniels
Committee on Health, Human Services & Elderly Affairs
127 Whitten Road
Milford, NH 03055-3228

January 24, 2009

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

Dear Rep Daniels,

It is encouraging that New Hampshire is considering an act relative to the use of long-term antibiotics for the treatment of Lyme disease. As a psychiatrist who works with late stage Lyme patients, I have seen many tragedies that could have been avoided by earlier and more effective diagnosis and treatment of Lyme and other tick-borne diseases. I have treated thousands of well documented cases of Lyme and other tick-borne diseases who are the failures as a result of lack of information, misinformation and the restricted approach towards Lyme and other tick-borne diseases. Some have come from New Hampshire. Some arrive at my office in wheel chairs, on stretchers and with canes while others look quite normal by casual observation. Although no two patients have exactly the same symptoms, I commonly see many cognitive, psychiatric, neurological and general medical symptoms that could have been prevented by earlier more effective treatment. My research and writings have focused upon the significant role of tick-borne diseases in causing different mental symptoms and some cases of autism spectrum disorder. A single case of autism incurs an average of $16 million in lifetime costs, mostly from public funds. [1] The high incidence of Lyme disease and the associated high incidence of autism spectrum disorders in Northeastern states is devastating in both

---

[1] Kogan MD, Blumberg SJ, Schieve LA et al. Prevalence of Parent-Reported Diagnosis of Autism Spectrum Disorder Among Children in the US, 2007. *Pediatrics*. 2009 Oct 5.

human and taxpayer costs and needs to be considered to prevent excessive human and financial costs in your healthcare system. [2] [3]

Unfortunately this epidemic is exacerbated by misinformation propagated by a small but highly influential group of individuals who portray themselves as representing mainstream medicine. The narrow and highly restrictive Lyme Disease Guidelines promulgated by the Infectious Disease Society of America (IDSA) are so extreme that the Connecticut Attorney General launched an antitrust investigation regarding the IDSA guideline development process and found that the guidelines were adopted by a panel biased with extensive conflicts of interest in pharmaceuticals, vaccines, diagnostic test kits, and insurance with no one representing the interests of patients on the panel.

In response to the controversial IDSA Lyme disease Guidelines, I submitted a challenge in the IDSA Guideline review process. The submission was supported by three medical societies—The New Jersey Psychiatric Association, the Medical Society of New Jersey and the International Lyme and Associated Diseases Society. These medical societies work to ensure the sanctity of the physician-patient relationship and advocate for the rights of patients and physicians alike and the delivery of the highest quality medical care which allows response to the patient's individual, varied needs in an ethical and compassionate environment. The Medical Society of New Jersey is the oldest professional society in the United States. These three organizations have a combined membership of 9,400 and a combined age of 327 years.

There are many forward thinking, highly motivated and compassionate physicians who recognize the seriousness of the Lyme disease epidemic and the value of effective treatment for these patients and their unborn children. However, there are also others who influence policy, who lack the vision or have competing interests that deny the full breadth and depth of these conditions. The teachings of the Father of Medicine, Hippocrates and the Father of American Medicine, Sir William Osler have always emphasized the value of listening carefully to the patient, using our best clinical judgment, individualizing the treatment plan and avoiding influences from third parties that compromise quality of care. We who follow this approach are the mainstream of traditional medicine.

As Americans we all have a passion for freedom and a resistance to any form of tyranny. Our ancestors were at Lexington, Concord and Normandy and our sons and daughters are currently in Afghanistan and Iraq to preserve freedom. The freedom to access the medically necessary healthcare treatments of our choice for Lyme disease or any other condition is as critical as the freedom of speech or religion or any other basic freedom. As Dr. Benjamin Rush, signer of the Declaration of Independence and personal

---

[2] Bransfield RC, Wulfman JS, Harvey WT, Usman AI: The association between tick-borne infections, Lyme borreliosis and autism spectrum disorders. *Med Hypotheses*. 70(5), 967-74, (2008).

[3] Bransfield RC. Preventable cases of autism: the relationship between chronic infectious diseases and neurological outcome. Pediatric Health. (2009) April 3(2) 125-140.

physician to George Washington stated—"Unless we put medical freedom into the Constitution, the time will come when medicine will organize into an undercover dictatorship to restrict the art of healing to one class of men and deny equal privileges to others. Physicians in New Hampshire today should have the same freedom to treat their patients my ancestor, Dr Thomas Wynne, had when he treated his patient, William Penn.

I am sure you will receive testimony from those who are invested in a restricted view of Lyme disease, however, the freedom of physicians who exercise a combination of their best clinical judgment with a fair and balanced review of the medical literature to develop new and more effective treatments to help these patients should not be silenced or intimidated by an external agenda. Physicians should be free to treat chronic persistent tick-borne infections without fear of retaliation by state agencies. This would lead to more physicians willing to treat chronic Lyme disease, with shorter waiting lists for appointments with doctors who have this very specialized expertise. Chronic Lyme disease is a significant issue for the nearly one million physicians in the United States, not just the IDSA which represents less than 1% of these physicians. In addition the 14 members who wrote the highly controversial guidelines represented 0.0016 of the membership of the IDSA. The personal opinions of such a small minority with conflicting interests should not dictate how the other 99.9999% of physicians in the United States should practice medicine.

The physicians in surrounding states cannot fully compensate for deficiencies in the current New Hampshire healthcare system. Physicians who treat chronic Lyme and other tick-borne diseases in New Hampshire should have the freedom to use their clinical judgment in diagnosing and treatment tick-borne illness. Please support the passage of HB 1326, AN ACT relative to the use of long-term antibiotics for the treatment of Lyme disease The Lyme and Related Tick-Borne Disease Education, Prevention and Treatment Act to protect quality healthcare for current and future generations.

Sincerely,

Robert C Bransfield, MD, DLFAPA, PC
President International Lyme and Associated Diseases Society
Distinguished Life Fellow American Psychiatric Association
Board Certified American Board of Psychiatry and Neurology
Certified in Psychopharmacology American Society of Clinical Psychopharmacology
Senior Vice President New Jersey Psychiatric Association
Clinical Associate Professor of Psychiatry RWJ-UMDNJ Medical School
Associate Director of Psychiatry and Chair of Psychiatric Quality Assurance Committee
Riverview Medical Center
American Psychiatric Association Work Group on Access to Care
American Psychiatric Association Work Group on Mental Health Parity

File Copy 1326

IDSA
Infectious Diseases Society of America

IDSA Headquarters
1300 Wilson Boulevard
Suite 300
Arlington, VA 22209
TEL: (703) 299-0200
FAX: (703) 299-0204
E-MAIL ADDRESS:
info@idsociety.org
WEBSITE:
www.idsociety.org

January 11, 2010

The Honorable Cindy Rosenwald
Committee on Health, Human Services, & Elderly Affairs
New Hampshire House of Representatives
101 Wellington Street
Nashua, NH 03064-1616

Dear Representative Rosenwald:

I write on behalf of the Infectious Diseases Society of America (IDSA) to urge you to oppose the enactment of New Hampshire House Bill 1326, which sanctions medically questionable treatments for Lyme disease. In urging your opposition to this legislation, our primary concern is to ensure the best quality in patient care and to protect the public's health and safety. To this end, we believe it is critically important that you be fully apprised of the widespread consensus within the medical and scientific community about the appropriate treatment of Lyme disease, as well as the medical community's concerns about unproven, potentially harmful treatments for so called "chronic" Lyme disease that are advocated by a small group of physicians.

IDSA represents more than 9,000 physicians and scientists and is widely recognized as the pre-eminent authority on infectious diseases (ID) in the United States. The Society's members focus on the epidemiology, diagnosis, investigation, prevention and treatment of infectious diseases in the U.S. and abroad. Our members care for patients of all ages with serious infections, including Lyme disease. In 2006, IDSA published revised practice guidelines for the clinical assessment, treatment, and prevention of Lyme disease. The development of guidelines requires the review of scientific and medical literature. IDSA's guidelines were developed by a 14-member panel of infectious diseases clinicians and researchers, including physicians with many years of clinical experience treating patients with Lyme disease.

As you know, Lyme disease is a tick-transmitted infection that can cause non-specific symptoms such as muscle and joint pain, fevers, chills, fatigue, and difficulties with concentration or memory loss. Some patients may continue to experience these symptoms even after a course of antibiotic therapy has killed the Lyme disease bacterium.

A small group of physicians have diagnosed such patients as having "chronic" Lyme disease. Many of these so called "chronic" Lyme diagnoses are supported by laboratory tests that are not evidence based and are not regulated by the Food and Drug and Administration. Such diagnoses and treatments are not supported by the IDSA practice guidelines, nor are they supported by Lyme disease guidelines published by the American Academy of Neurology, nor by publications from the

Centers for Disease Control and Prevention, the National Institutes of Health, the American College of Physicians, and the American Academy of Pediatrics, nor by the vast majority of experts in the field of ID medicine in this country and abroad. Even more troubling, physicians who diagnose "chronic" Lyme disease often advocate treating patients with repeated or prolonged courses of oral or intravenous antibiotics that have no proven value other than an anti- inflammatory response in some individuals, and may in fact do more harm than good.

The premise for prolonged antibiotic therapy for Lyme disease is the notion that some spirochetes can persist despite conventional treatment courses, thereby giving rise to the symptoms ascribed to chronic Lyme disease. Not only is this assertion microbiologically implausible, there are no convincing published scientific data that support the existence of chronic Lyme disease. Rather, carefully designed studies of Lyme disease have demonstrated that there is no difference in the measured improvement between patients receiving placebo and patients treated with antibiotics.

Most importantly, **not only is long-term antibiotic therapy for Lyme disease unnecessary, but the scientific evidence suggests that it may be dangerous, leading to potentially fatal infections of the bloodstream as a result of intravenous treatment**. Far from improving the patient's quality of life, prolonged antibiotic therapy may actually increase the patient's suffering. Also, although the bacteria that causes Lyme disease does not acquire resistance to antibiotics, long-term antibiotic exposure can lead to drug-resistance among other microorganisms, creating "superbugs" that cannot be treated with currently available drugs.

Notwithstanding the vast majority of ID physicians' belief that the medical evidence related to appropriate Lyme disease treatments is clear and accurately reflected in IDSA's Practice Guidelines for the Treatment of Lyme Disease, the Society recently reached an agreement with the Connecticut Attorney General to conduct a special and comprehensive review of the scientific and medical evidence related to Lyme disease treatments—this review is currently underway. IDSA believes that it is far better to allow time for this review to be completed rather than prematurely sanctioning potentially harmful treatment modalities through ill-advised state legislation.

While IDSA opposes enactment of House Bill 1326 for the reasons stated above, it supports the Health Committee's efforts to hold public hearings on Lyme disease later this month. IDSA believes that such hearings could play an important role in educating New Hampshire legislators and citizens about the controversy surrounding the treatment of Lyme disease. However, in order to ensure that legislators get a science-based assessment of appropriate treatments for Lyme disease, **IDSA strongly urges you to invite board-certified ID specialists who support evidence-based medicine to testify at all public hearings and we would be happy to help you identify such individuals.**

For more information on Lyme disease and the recommendations by the vast majority of experts in the field, please visit websites for IDSA (www.idsociety.org), the Centers for Disease Control and Prevention (www.cdc.gov), the National Institute of Allergy and Infectious Diseases (www.niaid.gov), the American Academy of Neurology (www.aan.com) or the American College of Physicians (www.acponline.org).

I hope you will contact Mark Leasure at IDSA if you have questions or would like the names of board-certified ID physicians who may be willing to provide further guidance on appropriate treatments for Lyme disease. Mr. Leasure may be reached at (703) 299-0200 or via e-mail at mleasure@idsociety.org.

Sincerely,

Richard J. Whitley

Richard Whitley, MD
President, IDSA

Enclosures:
IDSA's Practice Guidelines for the Treatment of Lyme Disease

David Whelan. "Lyme Inc. Ticks aren't the only parasites living off patients in borreliosis-prone areas." *Forbes*, March 12, 2007.

Feder et al. A Critical Appraisal of "Chronic Lyme Disease." New England Journal of Medicine, October 2007.

Jason Feifer. "Combat Zone. There's No Neutral Ground in War Of Information About Lyme Disease." Washington Post, May 15, 2007; HE01.

Jamie Talan. "A Rift Over Lyme Disease. Experts are split over diagnosis and treatment of the tick-borne illness." Newsday, May 22, 2007.

Complete Document

Can Be Viewed

In Bill Folder

File Copy 1326

A RIFT OVER LYME DISEASE, Experts are split over diagnosis and treatment of the tick-borne illness

[ALL EDITIONS]

Newsday - Long Island, N.Y.
Author: JAMIE TALAN. jamie.talan@newsday.com
Date: May 22, 2007
Start Page: B.12
Section: HEALTH
Text Word Count: 2116

Document Text

SIDEBAR: SYMPTOMS, TREATMENT, COMPLICATIONS, PRECAUTIONS (SEE END OF TEXT)

Kim Yastrzemski has been on and off intraveneous and oral antibiotics for close to eight years - one of thousands of people diagnosed with and treated for a chronic and persistent infection known as Lyme disease.

She doesn't remember an actual tick bite or classic bull's-eye rash, but her doctors found evidence that the common Borrelia bacteria have been in her body. Time and again, antibody tests to diagnose Lyme disease came back positive.

But this pesky bacterial bug - and the test used to diagnose exposure to it - have been at the heart of a raging controversy on the very definition of Lyme disease. Mainstream infectious disease experts argue that there is no evidence that Lyme borreliosis (infection) remains in the body after a few weeks to a month of antibiotic treatment. These doctors are not doubting that patients like Yastrzemski are suffering from real and persistent symptoms - from headaches to sheer exhaustion - but they question the trigger for these problems, and worry about the ongoing exposure to antibiotics.

On the other side, some maverick doctors have built thriving practices on the back of the bacterium, diagnosing Lyme for a laundry list of unexplained symptoms and a Lyme antibody test that picks up whether a person has ever been exposed to it. The antibody test is not a marker for active infection.

"There are a lot of people who think they have Lyme disease but don't," said Dr. Raymond Dattwyler, an infectious disease expert who once studied Lyme disease at University Hospital in Stony Brook and has since moved to New York Medical College in Valhalla. "We are not serving these people well. We have no definition for chronic Lyme disease or [know] that there are any effective treatments for these patients' ongoing symptoms."

Long-term questions

Dattwyler and other infectious disease doctors who treat Lyme disease argue that a minority of doctors have made it their business to diagnose and treat ongoing symptoms as a chronic Lyme infection while the real triggers for these symptoms can be ignored or missed.

Dattwyler said the government has thrown a lot of research money at studying persistent infection associated with Lyme disease, but the bacteria just aren't there after the acute infection is treated. In one multi-center study, led by Dr. Mark Klempner of Boston University School of Medicine, 129 patients with well-documented Lyme disease who were acutely treated but complained of lingering symptoms were split up to receive three months of either antibiotics or a placebo.

'No evidence of bacteria'

At several points during treatment and months later, patients were asked how they felt. The equation was always the same, no matter when they were asked: A third felt better, a third felt worse and the others said they felt no change. Kempner said he and his colleagues took samples of spinal fluid, blood and urine, searching for evidence of active infection.

"Over 750 lab exams," Klempner said. "And not a single person at any point in the study had evidence of the bacteria."

"They are suffering from something, but it isn't a persistent infection," Dattwyler said of the unexplained neurological and physical

Experts say that precautionary measures can be taken to avoid exposure to the bacterium. With summer around the corner, wear protective clothing (socks, long pants and long-sleeved shirts) when in wooded areas or in the grass nearby. Wear light-colored clothing so ticks are easier to spot. (Spraying clothing with the insecticide permethrin also helps keep ticks at bay. Repellents with DEET work, too, but beware of side effects and sensitivities to these products.)

Dattwyler said that many people find it hard to comply with these recommendations and advises that they examine their bodies, their children and clothing for ticks. Washing clothes in hot water also kills ticks.

According to the National Institute of Allergy and Infectious Diseases, ticks that transmit Lyme can be as small as a poppy seed, so check clothing and skin carefully. Check your pets for ticks, as well.

If you see a tick, use a tweezer to gently remove it. Don't squeeze its body because that can inadvertantly inject the bacterium into the skin. Then, use an antiseptic on the bite.

Most ticks do not transmit Lyme, but don't take chances. If a rash develops, call your doctor immediately.

- Jamie Talan

Abstract (Document Summary)

"There are a lot of people who think they have Lyme disease but don't," said Dr. Raymond Dattwyler, an infectious disease expert who once studied Lyme disease at University Hospital in Stony Brook and has since moved to New York Medical College in Valhalla. "We are not serving these people well. We have no definition for chronic Lyme disease or [know] that there are any effective treatments for these patients' ongoing symptoms."

"They are suffering from something, but it isn't a persistent infection," Dattwyler said of the unexplained neurological and physical problems. And it is this very fact, he said, that makes them vulnerable to the "Lyme" diagnosis. "Modern medicine doesn't address their needs well."

Organizations like Time for Lyme have referred to these guidelines as "repressive." In a news release issued last month, the group's founder and co-president, Debbie Sicillano, said: "At a time when Lyme and other tick-borne illnesses are becoming more prevalent ... some treatment guidelines are marginalizing our efforts to understand, diagnose, treat and cure this disease." Datwyller and others say these parent-run organizations believe the chronic symptoms are a sign of untreated bacterial infection and have sided themselves with those doctors who provide long-term antibiotic treatment.

File Copy 1326

Sports & Money

Forbes.com

Health

Lyme Inc.

David Whelan 03.12.07

Ticks aren't the only parasites living off patients in borreliosis-prone areas.

Three years ago Heather Jenkins, a 30-year-old mom in Huntersville, N.C., was constantly fatigued and prone to colds. Her internist referred her to Dr. Joseph Jemsek, a self-described "Lyme Literate" doctor. During the initial consultation he asked if she had been bitten by a tick or gotten a rash. No, she replied, but she had gone camping once in Tennessee. He suggested she may have picked up Lyme disease there and sent her blood to a California lab that specializes in tests for tick diseases. A week later the test results came back: She had been infected by *Borrelia burgdorferi*, the spirochete that causes Lyme disease.

Jemsek installed a tube in Jenkins' arm and every two weeks for a year and a half sold Jenkins a $3,000 course of Rocephin, a powerful antibiotic, to infuse on her own at home. When she developed infections around the catheter in her arm the nurse would switch it. When her arms wore out she got a port implanted in her chest. As she waited for Jemsek to treat her latest infection, she collapsed on the floor, vomiting. Drug-resistant bacteria had overtaken her entire body. Jenkins landed in a hospital intensive care unit for four weeks, barely surviving. A doctor at Carolina Medical Center, where she recovered, told her that their labs could find no evidence in her blood that she'd ever had Lyme. "I was outraged," she says, and is now suing Jemsek. The near-death odyssey cost her insurance company $400,000. The action is pending, and Jemsek has made no comment.

Lyme disease, with 20,000 cases reported annually, ranks low on the list of the most prevalent infectious diseases. But it ranks first in rancor generated in the medical community. The disease is caused by bacteria related to syphilis that enter the body through a tick bite. The typical Lyme infection responds to simple antibiotics, although symptoms like arthritis and fatigue may linger in a subset of patients. Researchers at academic medical centers who study the disease say that so-called chronic Lyme, or post-Lyme, is very rare, hard to detect and not treatable with any further doses of antibiotics. The mainstream doctors warn about an epidemic of bunk diagnoses and dangerous treatments. Insurers often refuse to cover the cost of treating chronic Lyme.

Arrayed against the establishment is a fraternity of Lyme specialists, many of whom have built large practices treating ostensible Lyme patients with expensive courses of antibiotics.

Last year the North Carolina state medical board brought Jemsek in for a disciplinary hearing. Ten patients testified to nightmarish experiences. A widower said his wife had died from a morphine overdose related to Jemsek's Lyme treatments. Jemsek disputed all the charges vigorously. He also had 200 supporters show up, many of whom believe he cured them of a terrible disease. The Lyme Disease Association, a group that supports Jemsek, says that 30 chronic Lyme doctors have been similarly targeted by medical boards. Jemsek ultimately received a "suspension with stay" that allows him to keep practicing.

The light penalty may reflect the power of Lyme support groups, which blast politicians with mail and phone calls to ensure their access to expensive care. Standing with them now is Connecticut Attorney General Richard Blumenthal, who has received awards from Lyme groups and late last year announced that he was investigating the Infectious Diseases Society of America, an 8,000-member organization of doctors trained to understand diseases like AIDS, malaria and tuberculosis. Their crime? Issuing Lyme treatment guidelines to doctors that warned against using long-term infused or oral antibiotics.

Blumenthal, who hasn't yet issued any lawsuits in the case, says that the IDSA's guidelines may be in violation of antitrust laws. "Lyme disease is an extraordinarily insidious and widespread problem in Connecticut. We want to make sure that patients and physicians have unfettered choices," he declares. Insurance companies, he goes on, may be colluding with the IDSA to deny care. It's an odd charge, since a 1996 policy statement from the Federal Trade Commission and the Department of Justice says that treatment guidelines issued by medical societies do not limit competition. "You want medicine to advance by debate, not hampered by lawsuits," says Robert Buchanan, a medical-antitrust attorney in Boston.

Despite intimidation from elected officials like Blumenthal, the establishment has scored some hits against Lyme specialists. In 1993 Vithaldis Shah, a New Jersey doctor, had his license yanked for five years for sickening Lyme patients with long-term antibiotic treatments and receiving a payment from the infusion company. In 1996 a doctor in Michigan was suspended after conspiring with a home infusion company and misdiagnosing Lyme patients. In 2000 a study described the death of an anonymous woman from complications arising from treating unsubstantiated Lyme with antibiotics.

In Connecticut Dr. Charles Jones, a pediatrician, is under investigation by the state medical board for prescribing, over the phone, antibiotics for chronic Lyme to two children in Nevada, a desert state with few ticks. Jones, who pulled up to a June hearing in a stretch limo to the cheers of fans, has testified that he did not finalize a Lyme diagnosis until he saw the children in person. Since the hearings began, more upset patients have joined the action against Jones. Blumenthal, however, has criticized the medical board for its investigation.

Mainstream doctors say their guidelines are based on scientific evidence. An early study identified 25 patients with gallstones or bile blockage resulting from antibiotic treatment of unsubstantiated chronic Lyme. A more recent study of infused antibiotics published in the *New England Journal of Medicine* was cut short after Lyme sufferers with persistent symptoms did not respond to a course of antibiotics any better than they did to a placebo. One patient getting antibiotics had a pulmonary embolism; another had gastrointestinal bleeding.

Another paper in the *Annals of Internal Medicine* calls chronic Lyme a "functional somatic syndrome," similar to other nebulous ailments like Gulf War Syndrome, chronic fatigue and fibromyalgia. Another study in the same journal found that 60% of Lyme disease patients lacked any evidence of previous or active Lyme infections. Some of these patients suffered from depression, arthritis or other diseases. "There are lot of people who have fatigue or musculoskeletal pain. We want to help them but not with long-term antibiotics," says Dr. Gary Wormser, an infectious disease expert at New York Medical College who helped write the guidelines that prompted Blumenthal's attack. After the latest idsa guidelines came out in November, Wormser and his Valhalla, N.Y. lab were the target of a protest attended by hundreds of chronic Lyme patients and supporters; one sign said "Wormser Lies ... Patients Die."

Many of the chronic Lyme patients are upset that their insurance companies won't cover unlimited treatments. WellPoint will pay for only four weeks of IV antibiotics, citing published peer-reviewed studies. But science is no match for the Internet, where Lyme patients swarm chat boards to bemoan the persecution of their doctors and egg on politicians. Some celebrities have joined in the fray, such as novelist Amy Tan and Daryl Hall of rock duo Hall and Oates, both of whom say they suffer from chronic Lyme.

Tan's doctor is Raphael Stricker, president of the International Lyme & Associated Diseases Society, which represents chronic Lyme doctors and patients. Stricker's San Francisco clinic also advertises its ability to treat obesity, infertility, erectile dysfunction and AIDS. In 1990 Stricker was forced out of UC, San Francisco after the school claimed he falsified data in what had been a seminal AIDS study. Before he discovered Lyme he spent two years as associate medical director at a penis enlargement clinic.

Stricker and many of his chronic Lyme allies send their blood tests to a California lab called Igenex, which was once investigated by Medicare and the state of California for pumping out too many positive tests. Nick S. Harris, chief executive of Igenex, says he passed both investigations easily, but in 2001 the federal Office of the Inspector General put Igenex on a list of noncompliant labs. It paid fines totaling $48,000. Harris says his firm has had no recent brushes with regulators. Harris says that his tests are more sensitive than ones given by lab giants Quest Diagnostics and LabCorp, yielding positive results 25% of the time. The big national labs typically return positive results 8% of the time. He acknowledges that his results are more open to interpretation, which could facilitate more positive diagnoses. "Patients, because of the Internet, have become my best salesmen," Harris says.

Jemsek, who in 2005 collected $6 million from Blue Cross Blue Shield of North Carolina, is still practicing, having declared his earlier practice bankrupt. He opened a new cash-only practice, spending $8 million on a building with a waterfall and grand piano. On the Internet patients exchange tips about how to keep seeing him. In his statement to the medical board after the stayed suspension of his license, Jemsek, who declines to be interviewed, said: "I've got 400 letters of support here, many single-spaced and several pages long."

File Copy HB 1326

File

January 13, 2010

RE: New Hampshire House Bill 1326

I am writing in support of the proposed legislation for HB 1326, which will authorize licensed physicians to prescribe long-term antibiotics for therapeutic purposes to patients diagnosed with Lyme Disease. I am a parent of a 13-year old daughter, who is currently suffering from an acute case of Lyme Disease. Our journey to receive the proper diagnosis and treatment has critically impacted my daughter and our family—medically, emotionally, and financially. Allow me to briefly describe my daughter *before* she contracted Lyme Disease. Vibrant with a huge heart and wonderful sense of humor, an honor roll student who loves school, a musician, a talented writer and actor, who loved long bike rides with me and long walks with our dog. She is a devoted friend. As a child with a chronic gastro-intestinal illness, she endured many painful and frightening medical procedures at various hospitals, but was always more concerned about the other children in the hospital who "would not get better." My daughter *today* has missed almost two months of school due to around the clock **acute pain** and swelling in her spine, neck, abdomen, ribs, and feet. She is finally able to walk without acute pain; she was in a wheelchair for over a month. She is struggling to keep up with the amount of missed and current schoolwork because she suffers from the "Lyme fog." She is unable to play piano or viola, and unable to bike ride or walk long distances. Just yesterday she told me that she cannot fulfill *her* dream of applying to private high schools and scholarships because it's too much pressure for her now. This is a glimpse into my daughter's world. The good news: we have been reassured by an out-of-state Lyme Literate physician (MD) who examined her on 12/29/09 that she will recover. He prescribed long-term antibiotics, and thus far, she is improving. (This physician is NOT covered by our health insurance, nor are the blood tests. Just this month her medical bills are $2,000. This is not an expense we can afford, but what is our alternative?!)

Here is the synopsis of our journey: My daughter sprained her ankle in early September 2009, (coincidental timing). The pediatrician sends her to an orthopedist who is puzzled by the swollen spine and pain (not in the ankle area), and refers us to a rheumatologist, who diagnoses her with Fibromyalgia. (At age 13?) When I called his office because my daughter has ACUTE pain and over-the-counter medications are not helping, I am told he will not speak with me until I take her for a mental health evaluation *and* that he doesn't see pediatric/adolescent patients! I take my daughter to a naturopath, who immediately runs extensive Lyme tests and puts her on antibiotics, because she presents as textbook symptomatic for Lyme. (Blood work results take about 3 weeks and naturopath doesn't want to risk wasting more time, as pain is acute.) Blood work returns and Lyme is confirmed. Pediatrician suggests an MRI, since pain is worsening, and we are sent to my daughter's neurosurgeon. MRI doesn't show spinal injury and MD doesn't believe in long-term antibiotics. Another trip to the pediatrician who states she won't prescribe long-term antibiotics and refers us to an Infectious Disease specialist whom we happen to know personally. The Infectious Disease MD looks at blood work, states without question that my daughter has Lyme (my daughter, mother and I are in the exam room when Infectious Disease MD conveys this) and states that she had one patient success story with a different antibiotic and extended usage. She prescribes the new antibiotic and indeed, my daughter begins to improve. We get an appointment with the aforementioned Lyme specialist, and I request my daughter's medical records – and read the Infectious Disease MD's report: "I agree with rheumatologist that patient has Fibromyalgia and mother insists I put daughter on antibiotics." (This revisionist history is quite alarming. Clearly, the Infectious Disease MD is concerned to state the truth on record. Given the fact that we live in Rockingham County, with the highest reported Lyme in NH, why aren't physicians educated in the diagnosis and treatment of this disease? My daughter is fortunate; she is improving. But, there is no excuse for being dismissed by physicians, including three ER visits, where she was prescribed Tylenol with Codeine despite the known acute side effects they had on her g.i. system. There are no words to describe seeing one's child in such acute pain for weeks on end, and no words to describe these physicians who are either so scared to lose their licenses by prescribing long-term antibiotics or are uninformed about diagnosing Lyme, that they allow their patients to suffer in this unspeakable manner. **I urge you to support passage of House Bill 1326.**

Sincerely,

Susan Kouguell, Stratham, NH

File
HB 1326

Comments for the Committee on Health and Human Services and Elderly Affairs about HB 1326, relative to allowing physicians to treat Lyme disease with antibiotics for more than 4 weeks without penalty.

My name is Nancy Ladd. I am a Librarian. Part of my job is to seek quality resources for people in my community to use as sources of information, and to assist with locating reliable and up-to-date information. This year I updated our resources on Lyme disease, and discovered that much has changed in the last ten years in the theories and knowledge of the disease. I also discovered that the disease is far from rare, is increasing rapidly in New Hampshire, has many possible presentations, and has some truly devastating effects, including death, if not treated properly.

Searching for medical studies on PubMed online for a person suffering from CNS neuropathy whose doctors had ruled out everything they could think of and were still mystified, I came across references to Lyme as a possible cause, and subsequently learned a great deal more about the disease. Through the person's experiences, and other people's stories, I also discovered a deep divide in the medical profession on how to diagnose and treat Lyme. This has led to my continued interest in and awareness of Lyme treatment, in all senses of the word.

I have discovered that the number of Lyme-infected deer ticks have been increasing dramatically (up to 70% infected) and moving northward in New Hampshire in recent years. I have learned that as of 2008, the number of new Lyme patients reported to the CDC from New Hampshire is now the highest per capita in the Nation, and that the rate per 100,000 in our southeastern counties is double our state average. I have learned that reported cases are considered by the CDC to only represent about 10-20% of people suffering from Lyme. I learned that under the new CDC surveillance guidelines there are an additional 40% of cases in New Hampshire serious enough that they have been reported as "probable" Lyme. By all indications, this is an epidemic with very serious implications for residents of our state.

There is no vaccine available for Lyme. Attempts to make vaccines were abandoned due to the development of serious Lyme-like symptoms in too many of those vaccinated. Prevention of this tick-born disease is also difficult, especially in a rural, forested state like New Hampshire. Treatment is only effective and easy if the disease is diagnosed early and treated aggressively with antibiotics in its early stages. Unfortunately this does not happen often enough, due to factors such as the absence in many people of some typical early symptoms such as a rash, and the shortcomings of blood tests.

Another reason for this failure to treat effectively is the apparent inability of many New Hampshire doctors to recognize or accept that their patients have Lyme. I have heard countless stories of doctors who have told their patients, even those with a visible rash and a tick- bite history, that "we don't have Lyme in New Hampshire" and who have declined to prescribe antibiotics. Others are using the restrictive CDC reporting standards as clinical diagnosis standards in spite of CDC advice to the contrary. I have even heard of a N.H. doctor who was recently sued, successfully, because he refused to believe his patient had Lyme and did not prescribe treatment. That patient was luckier than many – he was able to prove he had Lyme. However, he was unlucky like many others, in that it was not treated appropriately at an early stage.

A good analogy for Lyme disease is Syphilis, caused by another spirochete with similar characteristics and symptoms. Once the spirochetes have taken hold in various body tissues, it is extremely hard, if not impossible, to eradicate. Syphilis is routinely treated with long-term antibiotics. However, outdated and contested guidelines being pushed at doctors and enforced by insurance companies reject long-term antibiotics as valid for Lyme treatment, in spite of the evidence of thousands of patients who continue to relapse when antibiotic treatment is dropped, and improve again when it is resumed.

These contested guidelines, developed for the Infectious Diseases Society of America (IDSA) by researchers with ties to vaccine patent-holders and insurance companies, are outdated and are currently under mandated review due to an antitrust suit won in 2007 by the Connecticut Attorney General. Yet I found that even New Hampshire doctors who believe in the existence and severity of Lyme are nervous about prescribing antibiotics for more than the 2-4 weeks described in the old guidelines, out of fear of disciplinary action by the hospitals that employ them, or by medical boards, or being sued by Insurance companies. Patients thus are often denied the only treatment that makes their lives bearable and productive, or if lucky enough to find a doctor who will treat them longer in spite of the guidelines, are sometimes denied insurance coverage for testing or treatment. All because of outdated guidelines that have taken hold within the medical system.

HB 1326 is an essential step in helping to avert a growing health crisis, by allowing doctors to practice effectively without fear of penalty, and to provide treatment to increasing numbers of patients who have a very real need for relief from a severely debilitating or fatal condition. Its passage will also provide support for those fighting to change the guidelines, and those patients unable to get insurance coverage for their medical expenses. Other states that have passed similar Lyme legislation include Connecticut, Delaware, Maryland, Minnesota, New Jersey, and Rhode Island.

I urge the Committee to recommend passage of this Bill, and to educate the legislature about the issue. Some good resources include the California Lyme Disease Association (CALDA) at www.LymeDisease.org , the International Lyme and Associated Diseases Society (ILADS) at www.ILADS.org , the book "*Cure Unknown*" by science reporter Pamela Weintraub, and the award-winning documentary *Under Our Skin* (www.underourskin.com) which has been short-listed for an Academy Award.

Thank you for your time in considering my comments,

Nancy Ladd
483 Newmarket Rd
Warner NH
January 27, 2010

File Copy HB 1326

Dartmouth-Hitchcock Medical Center

Bryan J. Marsh, MD
Acting Chief, section of Infectious Disease
Associate Professor of Medicine

One Medical Center Drive
Lebanon, NH 03756
tel 603-650-8840
fax 603-650-6110
Bryan.J.Marsh@hitchcock.org

February 1, 2010

The Honorable Representative Cindy Rosenwald
Chairman
Health, Human Services & Elderly Affairs Committee
NH House of Representatives

Dear Chairman Rosenwald:

I am writing on behalf of Dartmouth-Hitchcock to urge your committee to find HB 1326 "inexpedient to legislate." As the Acting Chief of the Section of Infectious Disease and International Health at Dartmouth-Hitchcock Medical Center, I have reviewed this bill with all 14 other licensed Infectious Disease physicians in my group. Dartmouth-Hitchcock opposes this legislation for medical and legal reasons.

The medical reasons to oppose the legislation are many, but I will be brief. In essence, the legislation provides an imprimatur of validity to an approach to medical care that is distinctly at odds with contemporary evidence-based medicine, both for diagnosis and for treatment. Passage of this bill would thus compromise rather than improve the health and safety of our community, and do a disservice to people suffering from Lyme disease.

1) Diagnosis. The text of the legislation states ""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…" This absurdly vague definition of an infection and its complications, and clear attempt to exclude the import of diagnostic testing to confirm or exclude the diagnosis, would allow a "diagnosis and treatment plan…documented in the physician's medical record for the patient" to trump any and all objective evidence contrary to the supposed diagnosis. Medical science has come far from the times when a physician's hunch was adequate to justify significant and potentially harmful medical interventions, especially for a disease of known etiology and natural history.
2) Treatment. Therapy for people with infection with *Borrelia burgdorferi* has been extensively studied and <u>all</u> scientifically rigorous studies support the guidelines from the Infectious Disease Society of America, and <u>no</u> scientifically rigorous studies support the approach to therapy alluded to in this bill. House Bill 1326 attempts to use the legislative process to overcome the complete paucity of clinical trial data, experimental studies, theoretical rationale, and analogy from other infectious diseases to provide some validity for unvalidated approaches to treatment of infection with *Borrelia burgdorferi*.

The legal reason to oppose House Bill 1326 is simple: it attempts to provide an exclusion from disciplinary action for physicians for an idiosyncratically defined condition and thus precludes the fundamental responsibility of the Board of Medicine to oversee the professional activities of licensed physicians. There is absolutely no cogent argument that can be made to suggest that Lyme disease and infection with *Borrelia burgdorferi* is more exceptional than any other disease. Even if there were no scientific reasons to be suspect of this legislation, and even if the approach to diagnosis and treatment alluded to in the legislation were well validated, there would be no rationale for this exclusion. Given that the approach to care is without scientific support, and is contrary to the vast majority of expert opinion, this proposed exclusion should be even more suspect.

In conclusion, House Bill 1326 is an attempt to use legislation to create a protected area of medical care without any possible justification for this exception. This bill also attempts to subvert the contemporary scientific approach to medical care for patients with Lyme disease and suggests equivalence between well studied and validated approaches to diagnosis and treatment with one dependant on hunch and anecdotal experience. Public health and safety and physician accountability to their profession and their patients would both be compromised should this bill be enacted.

Sincerely yours,

Bryan J. Marsh, M.D.

File Copy HB 1326

Tony Fallon Architecture
501 Barn Door Gap
Strafford New Hampshire 03884-6233
603 - 269-3209
http://tonyfallon.com

29 January 2010

House of Representatives
Health, Human Services & Elderly Affairs

HB 1326

Gentles:

that I am amazed by and appreciate very much.

thoughts but as the planned for testimony struck off on a different track, I wanted to copy you with it. Below this cover note is what I had planned to deliver orally.

issue." I'd like to illustrate. At 53 I still play hockey in the 18 and over, full check, Capital City Hockey League. With this I understand the concept of a full contact sport very well. The league

inappropriate and damaging hits on doctors being made to scare them into not properly treating those with Lyme Disease. This leads to a double infraction of damage to the business of a doctor

I know 4 doctors from New Hampshire who have been inappropriately harassed due to the absence of rules. We need bring this topic out of the chaotic Wild West state that it is in and

Anthony Dreux Fallon

I thank Jesus, God, & The Holy Spirit for this gorgeous milieu of creation that is so beautiful & amazing at each scale, location, and time. I pretty much daily still childishly marvel

Now with this bounteous beauty there are of course things that get out of line and become organized other than optimally. One of those topics that is not organized optimally and we are having a conversation about today is our response to Lyme Disease, which is caused by the Borrellia Burgdorferi Bacteria, and it's host of co infections. Children of my age used to spend a lot of time watching shows and movies about the wild west. For the last 28 years my family has been living in today's wild west, Lyme Disease Treatment Chaos. My wife, Erin Fallon who testified earlier, has lived in it longer.

The other than optimal organization of Lyme Response stems from the root cause of declaring that it doesn't exist in a chronic format, to setting inappropriate protocols for initial response to tick bites that can lead more people to have chronic infections, to attacking doctors for prescribing proper treatments, to school districts dodging proper accommodations, to not recognizing the probable connections between Lyme and the many mystery diseases of Lou Gherig's Disease, Dimentia, and Fibromyalgia, to of course the suffering of the patients and their families with a rolling recurring ever changing host of symptoms that you have heard so much of today.

I commend to you a book that lays out the history of the disease pretty dryly and factually, Healing Lyme by Stephen Burner. This is a disease that has been around forever, changes what it does, how it looks, and how it attacks, where it attacks, and becomes active and then dormant and then active. It is difficult to detect and there are many labs and doctors that do not understand how to see if it is there since the dormant state as a cyst is so different from the active state.

My son in law is pursuing a doctorate in molecular ecology. He is a pretty smart guy with regards to biology. I remember distinctly his body language reaction to learning of all the wiles and ways of Borrellia Burgdorferi. With it's unique ability to cross into the otherwise super protected separate blood system dedicated to the brain and spinal cord, how it gets into a corkscrew to burrow where it wants, how it can change states, how it mimics body makeup to avoid the body's immune system, caused him to shudder at this very "nasty" disease. It is clearly not a one dimensional challenge.

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.

FEB. 1, 2010
File Copy 1326

To: NH House Committee on Health, Human Services and Elderly Affairs

From: Douglas R. Newton and Nancy Ladd both of Warner NH

We testified at last week's hearing on HB 1326 relative to allowing physicians to treat Lyme disease with antibiotics for more than 4 weeks without penalty. You have copies of our testimony.

As you consider action on HB 1326 to protect doctors who treat Lyme disease, please consider what we see as the essence of 5 hours of testimony:

1) Committee members were understandably confused about the need for this legislation and surprised at the crowd of passionate constituents lobbying for it.

2) Three doctors testified against HB 1326 by stating the <u>official</u> position of the medical community, which is summarized in the "Guidelines for the Treatment of Lyme Disease" by the Infectious Disease Society of America:

   a) Chronic, long term infection with Borrelia burgdorferi (the bacteria that causes Lyme) does not exist. If a patient has had 4 weeks of an appropriate antibiotic they no longer have a Lyme infection.

   b) Long term antibiotic therapy does not work to treat symptoms still present after 4 weeks of treatment.

3) One doctor (whose daughter had been sick with Lyme disease), and every Lyme patient who testified, described a chronic long term infection that took years to resolve if not treated aggressively within the first month of infection, and which, once established, responded only to long courses of antibiotics.

4) No Lyme patient mentioned the name of the NH doctor who was treating them (although we are proud of and grateful to doctors who are

willing to treat Lyme). This was to protect their doctors, who have expressed fear of censure.

5) Many Lyme patients described the difficulty of finding a NH doctor willing to test for, diagnose or treat Lyme disease. Several Lyme patients testified that they had to go out of state to get medical treatment.

6) Some Lyme patients said their insurance companies refused to pay for antibiotics after four weeks, even though they were still sick and their doctors felt they needed to continue treatment.

In our view, these are the salient points of 5 hours of testimony. The disconnect between the official medical view (2) and the reality of the disease (3,4,5, 6) is the source of much suffering and anger, and is why we need to protect doctors who treat Lyme.

We thank you for your time spent listening and learning about the need for this legislation, and urge you to take what may seem like an unusual legislative step, to be sure that New Hampshire residents can get the medical care they need. Lyme disease and it's lack of adequate treatment has the potential for becoming a health issue far worse than AIDS/HIV or H1N1 in terms of numbers and the impact on productivity and quality of life. Your prompt action can help avert much pain and suffering.

Sincerely,

Douglas R Newton Nancy Ladd

Douglas Newton and Nancy Ladd

483 Newmarket Rd.

Warner NH

Voting Sheets

HOUSE COMMITTEE ON HEALTH, HUMAN SERVICES AND ELDERLY AFFAIRS

EXECUTIVE SESSION on HB 1326

BILL TITLE: **relative to the use of long-term antibiotics for the treatment of Lyme disease.**

DATE: February 2, 2010

LOB ROOM: 205

Amendments:

Sponsor: Rep. OLS Document #:

Sponsor: Rep. OLS Document #:

Sponsor: Rep. OLS Document #:

Motions: OTP, OTP/A, ITL, [✓ Interim Study] (Please circle one.)

Moved by Rep. T. Donovan

Seconded by Rep. C. McMahon

Vote: 18-1 (Please attach record of roll call vote.)

Motions: OTP, OTP/A, ITL, Interim Study (Please circle one.)

Moved by Rep.

Seconded by Rep.

Vote: (Please attach record of roll call vote.)

CONSENT CALENDAR VOTE:

(Vote to place on Consent Calendar must be unanimous.)

Statement of Intent: Refer to Committee Report

Respectfully submitted,

Rep. Joan H. Schulze, Clerk
Rep. Joan H. Schulze

HOUSE COMMITTEE ON HEALTH, HUMAN SERVICES AND ELDERLY AFFAIRS

EXECUTIVE SESSION on HB 1326

BILL TITLE: **relative to the use of long-term antibiotics for the treatment of Lyme disease.**

DATE: 2/2/2010

LOB ROOM: 205

Amendments:

Sponsor: Rep. OLS Document #:

Sponsor: Rep. OLS Document #:

Sponsor: Rep. OLS Document #:

Motions: OTP, OTP/A, ITL, [✓ Interim Study] (Please circle one.)

Moved by Rep. DONOVAN

Seconded by Rep. MC MAHON

Vote: 18-1 (Please attach record of roll call vote.)

Motions: OTP, OTP/A, ITL, Interim Study (Please circle one.)

Moved by Rep.

Seconded by Rep.

Vote: (Please attach record of roll call vote.)

CONSENT CALENDAR VOTE:

(Vote to place on Consent Calendar must be unanimous.) Regular

Statement of Intent: Refer to Committee Report

Respectfully submitted,

Rep. Joan H. Schulze, Clerk

Susan Emerson

OFFICE OF THE HOUSE CLERK 2009 SESSION

HEALTH, HUMAN SERVICES & ELDERLY AFFAIRS

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

PH Date: 1 / 28 / 2010 Exec Session Date: 2 / 2 / 2010

Motion: Interim Study Amendment #:

MEMBER	YEAS	NAYS
Rosenwald, Cindy, Chairman	17	
Donovan, Thomas E, V Chairman	1	
French, Barbara C	2	
Schulze, Joan H, Clerk		
Tilton, Joy K	3	
Butcher, Suzanne S	4	
Bridgham, Robert G	5	
Merrick, Evalyn S	6	
Russell, Trinka T	7	
DiPentima, Rich T	8	
Miller, Kate W	9	
Batula, Peter L	10	
McMahon, Charles E	11	
Pilliod, James P	12	
Emerson, Susan	13	
Case, Frank G	14	
Millham, Alida I	15	
Wells, Roger G	16	
Cebrowski, John W		~~17~~ 1
Kotowski, Frank R	18	
TOTAL VOTE:	18	1

Printed: 1/12/2009

Committee
Report

REGULAR CALENDAR

February 10, 2010

HOUSE OF REPRESENTATIVES

REPORT OF COMMITTEE

The Majority of the Committee on HEALTH, HUMAN SERVICES & ELDERLY AFFAIRS to which was referred HB1326,

AN ACT relative to the use of long-term antibiotics for the treatment of Lyme disease. Having considered the same, report the same with the recommendation that the bill be REFERRED FOR INTERIM STUDY.

Rep. Thomas E Donovan

FOR THE MAJORITY OF THE COMMITTEE

Original: House Clerk
Cc: Committee Bill File

MAJORITY
COMMITTEE REPORT

Committee:	**HEALTH, HUMAN SERVICES & ELDERLY AFFAIRS**
Bill Number:	**HB1326**
Title:	**relative to the use of long-term antibiotics for the treatment of Lyme disease.**
Date:	**February 2, 2010**
Consent Calendar:	**NO**
Recommendation:	**REFER TO COMMITTEE FOR INTERIM STUDY**

STATEMENT OF INTENT

While this bill does not legislate specific medical care, it does create a policy precedent by limiting physicians' ability to regulate themselves in the practice of medicine. Specifically, the bill carves out the Board of Medicine's ability to oversee physicians for one treatment method for one disease process: Lyme disease. The Board of Medicine does not actually have the authority to recommend or enforce specific treatment guidelines for any area of medical care, but they are charged broadly to "protect the public from the incompetent, unprofessional, or impaired practice of medicine." The committee believes that all patients deserve protection and that carving out one group of patients from this important safeguard could have far-reaching consequences. Treatment guidelines are always recommendations, not mandates, and the decision about treatment is always left to the judgment of the individual physician. Over the course of more than five hours in the public hearing, the committee heard conflicting testimony about barriers to long term antibiotic treatment for chronic symptoms of Lyme disease. Specifically, we learned that there has never been a complaint filed with the Board of Medicine about a New Hampshire physician prescribing long term antibiotic therapy for Lyme disease, and the two physicians who testified in favor of the bill both stated they had never personally felt in danger of board sanction. However, there was public testimony that physicians are, in fact, reluctant to prescribe this treatment because of fear of sanction by the Board of Medicine. We heard implication that physicians may be reluctant to prescribe this treatment because of fear of insurance companies, but this bill does not regulate insurance companies. We also heard testimony by supporters that this bill is necessary to protect doctors, yet the bill is opposed both by the New Hampshire Medical Society, which represents most doctors in New Hampshire, and Dartmouth Hitchcock, our largest network of providers. Therefore, the committee would like the opportunity to study the effect of similar legislation in Rhode Island and Connecticut on the increase in the number of physicians who are willing to prescribe such treatment after legislation is enacted to remove the licensing board's oversight. The committee further heard of a financial barrier to treatment because insurance companies are unwilling to cover a particular form of diagnostic testing and long term antibiotic therapy, which we heard could be very expensive. Although the bill is not an insurance mandate, the committee would like the opportunity to study whether Rhode Island's insurance mandate has had a positive impact on the number of doctors willing to see this group of patients and patients' ability to afford treatment. The committee heard no testimony from Medicaid patients on their desire or ability to receive this treatment, but we think that would be meaningful too. Finally, the committee would like the opportunity to discuss Lyme disease with the department's division of public health and the Board of Medicine, through the Health and Human Services Oversight Committee. In summary, the committee believes we do not yet have enough information to make a final determination on this policy and, therefore, recommend interim study as the appropriate direction.

Vote 18-1

Rep. Thomas E Donovan
FOR THE MAJORITY

Original: House Clerk
Cc: Committee Bill File

REGULAR CALENDAR

HEALTH, HUMAN SERVICES & ELDERLY AFFAIRS
HB1326, relative to the use of long-term antibiotics for the treatment of Lyme disease. **REFER TO COMMITTEE FOR INTERIM STUDY.**
Rep. Thomas E Donovan for the **Majority** of HEALTH, HUMAN SERVICES & ELDERLY AFFAIRS. While this bill does not legislate specific medical care, it does create a policy precedent by limiting physicians' ability to regulate themselves in the practice of medicine. Specifically, the bill carves out the Board of Medicine's ability to oversee physicians for one treatment method for one disease process: Lyme disease. The Board of Medicine does not actually have the authority to recommend or enforce specific treatment guidelines for any area of medical care, but they are charged broadly to "protect the public from the incompetent, unprofessional, or impaired practice of medicine." The committee believes that all patients deserve protection and that carving out one group of patients from this important safeguard could have far-reaching consequences. Treatment guidelines are always recommendations, not mandates, and the decision about treatment is always left to the judgment of the individual physician. Over the course of more than five hours in the public hearing, the committee heard conflicting testimony about barriers to long term antibiotic treatment for chronic symptoms of Lyme disease. Specifically, we learned that there has never been a complaint filed with the Board of Medicine about a New Hampshire physician prescribing long term antibiotic therapy for Lyme disease, and the two physicians who testified in favor of the bill both stated they had never personally felt in danger of board sanction. However, there was public testimony that physicians are, in fact, reluctant to prescribe this treatment because of fear of sanction by the Board of Medicine. We heard implication that physicians may be reluctant to prescribe this treatment because of fear of insurance companies, but this bill does not regulate insurance companies. We also heard testimony by supporters that this bill is necessary to protect doctors, yet the bill is opposed both by the New Hampshire Medical Society, which represents most doctors in New Hampshire, and Dartmouth Hitchcock, our largest network of providers. Therefore, the committee would like the opportunity to study the effect of similar legislation in Rhode Island and Connecticut on the increase in the number of physicians who are willing to prescribe such treatment after legislation is enacted to remove the licensing board's oversight. The committee further heard of a financial barrier to treatment because insurance companies are unwilling to cover a particular form of diagnostic testing and long term antibiotic therapy, which we heard could be very expensive. Although the bill is not an insurance mandate, the committee would like the opportunity to study whether Rhode Island's insurance mandate has had a positive impact on the number of doctors willing to see this group of patients and patients' ability to afford treatment. The committee heard no testimony from Medicaid patients on their desire or ability to receive this treatment, but we think that would be meaningful too. Finally, the committee would like the opportunity to discuss Lyme disease with the department's division of public health and the Board of Medicine, through the Health and Human Services Oversight Committee. In summary, the committee believes we do not yet have enough information to make a final determination on this policy and, therefore, recommend interim study as the appropriate direction.

Vote 18-1.

Original: House Clerk
Cc: Committee Bill File

HB 1326 MAJ. T. Donovan Interim Study 18-1 RC

While this bill does not legislate specific medical care, it does create a policy precedent by limiting physicians' ability to regulate themselves in the practice of medicine. Specifically, the bill carves out the Board of Medicine's ability to oversee physicians for one treatment method for one disease process: Lyme disease. The Board of Medicine does not actually have the authority to recommend or enforce specific treatment guidelines for any area of medical care, but they are charged broadly to "protect the public from the incompetent, unprofessional, or impaired practice of medicine." The committee believes that all patients deserve protection and that carving out one group of patients from this important safeguard could have far-reaching consequences. Treatment guidelines are always recommendations, not mandates, and the decision about treatment is always left to the judgment of the individual physician. Over the course of more than five hours in the public hearing, the committee heard conflicting testimony about barriers to long term antibiotic treatment for chronic symptoms of Lyme disease. Specifically, we learned that there has never been a complaint filed with the Board of Medicine about a New Hampshire physician prescribing long term antibiotic therapy for Lyme disease, and the two physicians who testified in favor of the bill both stated they had never personally felt in danger of board sanction. However, there was public testimony that physicians are, in fact, reluctant to prescribe this treatment because of fear of sanction by the Board of Medicine. We heard implication that physicians may be reluctant to prescribe this treatment because of fear of insurance companies, but this bill does not regulate insurance companies. We also heard testimony by supporters that this bill is necessary to protect doctors, yet the bill is opposed both by the New Hampshire Medical Society, which represents most doctors in New Hampshire, and Dartmouth Hitchcock, our largest network of providers. Therefore, the committee would like the opportunity to study the effect of similar legislation in Rhode Island and Connecticut on the increase in the number of physicians who are willing to prescribe such treatment after legislation is enacted to remove the licensing board's oversight. The committee further heard of a financial barrier to treatment because insurance companies are unwilling to cover a particular form of diagnostic testing and long term antibiotic therapy, which we heard could be very expensive. Although the bill is not an insurance mandate, the committee would like the opportunity to study whether Rhode Island's insurance mandate has had a positive impact on the number of doctors willing to see this group of patients and patients' ability to afford treatment. The committee heard no testimony from Medicaid patients on their desire or ability to receive this treatment, but we think that would be meaningful too. Finally, the committee would like the opportunity to discuss Lyme disease with the department's division of public health and the Board of Medicine, through the Health and Human Services Oversight Committee. In summary, the committee believes we do not yet have enough information to make a final determination on this policy and, therefore, recommend interim study as the appropriate direction.

Rep Donovan

COMMITTEE REPORT

COMMITTEE: Relative to the use of long term antibiotics for the treatment of Lyme Disease

BILL NUMBER: HB 1326

TITLE: Relative to the use of long term antibiotics for the treatment of Lyme Disease

DATE: 2-2-2010 **CONSENT CALENDAR:** YES ☐ NO ☒

☐ **OUGHT TO PASS**

☐ **OUGHT TO PASS W/ AMENDMENT**

☐ **INEXPEDIENT TO LEGISLATE**

☒ **INTERIM STUDY** (Available only 2nd year of biennium)

Amendment No. ____________

STATEMENT OF INTENT:

COMMITTEE VOTE: 18-1

RESPECTFULLY SUBMITTED,

Rep. [illegible] Donovan
For the Committee

CR

- Copy to Committee Bill File
- Use Another Report for Minority Report

Rev. 02/01/07 - Yellow

HB 1326

While this bill does not legislate specific medical care, it does create a policy precedent by limiting physicians' ability to regulate themselves in the practice of medicine. Specifically, the bill carves out the Board of Medicine's ability to oversee physicians for one treatment method for one disease process: Lyme disease. The Board of Medicine does not actually have the authority to recommend or enforce specific treatment guidelines for any area of medical care, but they are charged broadly to "protect the public from the incompetent, unprofessional, or impaired practice of medicine." The committee believes that all patients deserve protection and that carving out one group of patients from this important safeguard could have far-reaching consequences. Treatment guidelines are always recommendations, not mandates, and the decision about treatment is always left to the judgment of the individual physician. Over the course of more than five hours in the public hearing, the committee heard conflicting testimony about barriers to long term antibiotic treatment for chronic symptoms of Lyme disease. Specifically, we learned that there has never been a complaint filed with the Board of Medicine about a New Hampshire physician prescribing long term antibiotic therapy for Lyme disease, and the two physicians who testified in favor of the bill both stated they had never personally felt in danger of board sanction. However, there was public testimony that physicians are, in fact, reluctant to prescribe this treatment because of fear of sanction by the Board of Medicine. We heard implication that physicians may be reluctant to prescribe this treatment because of fear of insurance companies, but this bill does not regulate insurance companies. We also heard testimony by supporters that this bill is necessary to protect doctors, yet the bill is opposed both by the New Hampshire Medical Society, which represents most doctors in New Hampshire, and Dartmouth Hitchcock, our largest network of providers. Therefore, the committee would like the opportunity to study the effect of similar legislation in Rhode Island and Connecticut on the increase in the number of physicians who are willing to prescribe such treatment after legislation is enacted to remove the licensing board's oversight. The committee further heard of a financial barrier to treatment because insurance companies are unwilling to cover a particular form of diagnostic testing and long term antibiotic therapy, which we heard could be very expensive. Although the bill is not an insurance mandate, the committee would like the opportunity to study whether Rhode Island's insurance mandate has had a positive impact on the number of doctors willing to see this group of patients and patients' ability to afford treatment. The committee heard no testimony from Medicaid patients on their desire or ability to receive this treatment, but we think that would be meaningful too. Finally, the committee would like the opportunity to discuss Lyme disease with the department's division of public health and the Board of Medicine, through the Health and Human Services Oversight Committee. In summary, the committee believes we do not yet have enough information to make a final determination on this policy and, therefore, recommend interim study as the appropriate direction.

Thomas E Donovan

CR

REGULAR CALENDAR

February 10, 2010

HOUSE OF REPRESENTATIVES

REPORT OF COMMITTEE

The Minority of the Committee on HEALTH, HUMAN SERVICES & ELDERLY AFFAIRS to which was referred HB1326,

AN ACT relative to the use of long-term antibiotics for the treatment of Lyme disease. Having considered the same, and being unable to agree with the Majority, report with the recommendation that the bill OUGHT TO PASS.

Rep. John W Cebrowski

FOR THE MINORITY OF THE COMMITTEE

Original: House Clerk
Cc: Committee Bill File

MINORITY
COMMITTEE REPORT

Committee:	**HEALTH, HUMAN SERVICES & ELDERLY AFFAIRS**
Bill Number:	**HB1326**
Title:	**relative to the use of long-term antibiotics for the treatment of Lyme disease.**
Date:	**February 2, 2010**
Consent Calendar:	**NO**
Recommendation:	**OUGHT TO PASS**

STATEMENT OF INTENT

This bill seeks to protect New Hampshire licensed Lyme treating physicians while providing therapeutic care to patients diagnosed with symptoms of chronic Lyme disease. This bill does not legislate medical care. The minority strongly believes that medical care should not have to be made difficult to obtain while the two competing professional organizations, the Infectious Disease Society of America and the International Lyme and Associated Diseases Society resolve their differences.

Rep. John W Cebrowski
FOR THE MINORITY

Original: House Clerk
Cc: Committee Bill File

REGULAR CALENDAR

HEALTH, HUMAN SERVICES & ELDERLY AFFAIRS
HB1326, relative to the use of long-term antibiotics for the treatment of Lyme disease. **OUGHT TO PASS.**
Rep. John W Cebrowski for the **Minority** of HEALTH, HUMAN SERVICES & ELDERLY AFFAIRS. This bill seeks to protect New Hampshire licensed Lyme treating physicians while providing therapeutic care to patients diagnosed with symptoms of chronic Lyme disease. This bill does not legislate medical care. The minority strongly believes that medical care should not have to be made difficult to obtain while the two competing professional organizations, the Infectious Disease Society of America and the International Lyme and Associated Diseases Society resolve their differences.

Original: House Clerk
Cc: Committee Bill File

HB 1326 Minority J. Cebrowski OTP RC

This bill seeks to protect New Hampshire licensed Lyme treating physicians while providing therapeutic care to patients diagnosed with symptoms of chronic Lyme disease. This bill does not legislate medical care. The minority strongly believes that medical care should not have to be made difficult to obtain while the two competing professional organizations, the Infectious Disease Society of America and the International Lyme and Associated Diseases Society resolve their differences.

MINORITY REPORT

COMMITTEE: HEALTH + HUMAN SERVICES

BILL NUMBER: HB-1326

TITLE: AN ACT RELATIVE TO THE USE of ANTIBIOTICS FOR THE TREATMENT of LYME DISEASE

DATE: 2-2-10 **CONSENT CALENDAR:** YES ☐ NO ☒

☑ OUGHT TO PASS

☐ OUGHT TO PASS W/ AMENDMENT

☐ INEXPEDIENT TO LEGISLATE

☐ INTERIM STUDY (Available only 2nd year of biennium)

Amendment No. ________

STATEMENT OF INTENT:

REP. JOHN CEBROWSKI for the MINORITY of Health, Human Services and Elderly Affairs. This bill seeks to protect New Hampshire licensed Lyme treating physicians while providing therapeutic care to patients diagnosed with symptoms of chronic Lyme disease. This bill does not legislate medical care. The minority strongly believes that medical care should not have to be made difficult to obtain while the two competing professional organizations, The Infectious Disease Society of America and the International Lyme and Associated Diseases Society resolve their differences.

COMMITTEE VOTE: ________

RESPECTFULLY SUBMITTED,

Rep. John Cebrowski

For the Minority

- Copy to Committee Bill File

Rev. 02/01/07 - Blue