

Lyme & Tick-Borne Diseases in the US 2019: 44 Years into Lyme

Lyme & Tick-Borne Diseases Congressional Town Meeting

Wall, NJ

May 29, 2019

Lyme Disease Association, Inc.

Patricia V. Smith, President

American Dog Ticks

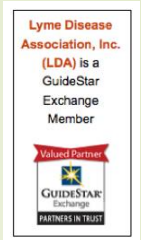


www.LymeDiseaseAssociation.org

<https://www.facebook.com/LymeDiseaseAssociation>

About Lyme Disease Association, Inc.

- National non profit 501(c)(3), volunteer run, 28 yrs. of service
- Mission: raise \$\$ research, education, prevention, support, 97% to programs
- Awarded 115 research grants, LDA-research 50 journal publications
- Endowed Columbia Lyme & TBD Research Center w/ then TFL
- Partner w/ Environmental Protection Agency PESP Program (tick avoidance)
- 13 years in Combined Federal Campaign (CFC)
- Partners with 40+ US Lyme organizations: LDAnet umbrella
- LDA President Testified before:
 - House Foreign Relations Committee, Global Health/Human Rights Subcom.
 - Energy & Commerce Health Subcommittee
- Briefed Senate Aging Committee 2019



www.LymeDiseaseAssociation.org Newly updated website



LDA Funding Projects in Various Stages

- ❑ Columbia University, Christine Ann Denny, PhD
 - Identifying the neural ensembles mediating cognitive abnormalities following *Borrelia burgdorferi* infection
- ❑ University of Washington, Effie E. Bastounis, PhD
 - Biochemical alterations of endothelial cells infected with *Borrelia burgdorferi*
- ❑ Northeast Wildlife DNA Laboratory;Pike County Comm.(PA)
Nicole Chinnici, Lab Director
 - Pike County Tick-Borne Disease Base Line Study
- ❑ Rutgers University, NJ Medical School, S. Schutzer, MD
 - Sequencing Project *Borrelia* & other TBDs
- ❑ Shenandoah University School of Pharmacy- Lyon, PhD
 - Genetic variations & chronic Lyme
- ❑ Columbia Lyme & TBD Research Center
 - Various projects





Lyme Disease Association, Inc.
Research, education, prevention & patient support
LDA: 28 years of patients helping patients!

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2019 LDA Conference

REGISTER NOW!

Lyme Disease Association Inc. 20th Annual
Lyme/TBD Scientific CME Conference
September 21-22, 2019 Philadelphia, PA



- Designed for physicians & researchers, open to the public
- Brian A. Fallon, MD
Columbia Vagelos College
of Physicians & Surgeons,
Conference Director

[General Information](#)
[Registration Page](#)
[Scholarship Info](#)

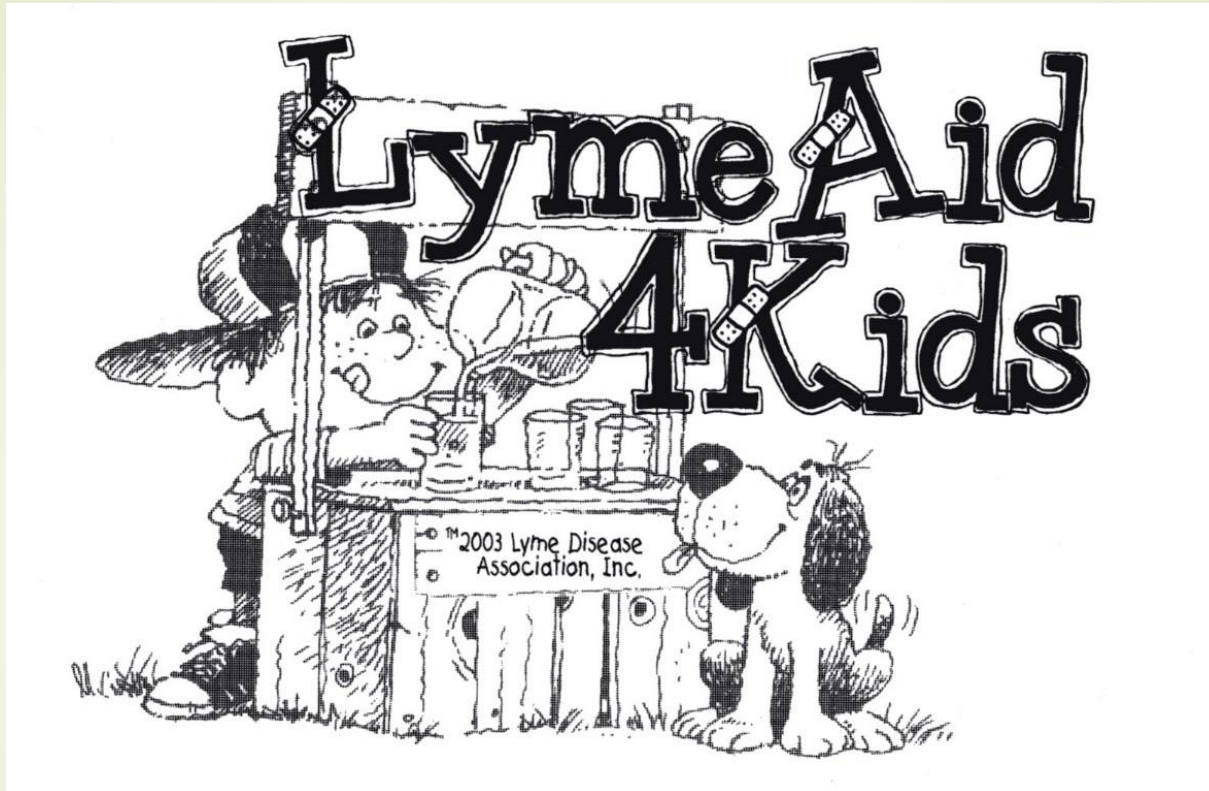
LDA 20th Annual CME Conference

Lyme & Other Tick-Borne Diseases: 20th Annual Scientific Update Jointly sponsored by Columbia University

Philadelphia Hilton Penn's Landing
September 21, 22, 2019



LymeAid 4 Kids Grant Program



- LymeAid 4 Kids (LA4K) fund began in 2003
- Has helped children all over the U.S.
- Developed with help of author Amy Tan
- For children who do not have/receive insurance coverage
- \$345,400 to date provided by LDA



Lyme Disease Association Materials

LymeR Primer
Learn About Lyme & Other Tick-Borne Diseases

- Lyme disease
- Anaplasmosis
- Babesiosis
- Bartonellosis
- Borrelia burgdorferi
- Colorado tick fever
- Ehrlichiosis
- Powassan encephalitis
- Acute Rocky Mountain spotted fever

The ABC's of Lyme Disease

TICK REMOVAL

- Do not burn or use any substance on tick.
- Do not grasp, squeeze or twist the body of tick.
- Grasp tick close to skin with tweezers.
- Pull tick straight out.
- Use sunlight on skin afterward.
- Disinfect hands thoroughly.

TICK IDENTIFICATION

Ixodes scapularis (deer tick, blacklegged tick)
Found Northeast, Upper Midwest, Tennessee, Lyme, Lakehurst, Longmeadow, Powassan, Connecticut, New Jersey, Delaware, Maryland, Virginia

Amblyomma americanum (lone star tick)
Found Eastern U.S., Tennessee, Kansas, West Virginia, Oklahoma, South Carolina, North Carolina, Virginia, Maryland, Delaware, Pennsylvania, New Jersey, New York, Connecticut, Massachusetts, Rhode Island, Vermont, New Hampshire, Maine, Alaska, Hawaii

Dermacentor variabilis (dog tick)
Found All U.S., Tennessee, Rocky Mountain spotted fever, Lyme, Lakehurst, Kansas, West Virginia, Oklahoma, South Carolina, North Carolina, Virginia, Maryland, Delaware, Pennsylvania, New Jersey, New York, Connecticut, Massachusetts, Rhode Island, Vermont, New Hampshire, Maine, Alaska, Hawaii

Ixodes pacificus (blacklegged tick)
Found Far West, Tennessee, Lyme, Lakehurst, Longmeadow, Connecticut, Massachusetts, Rhode Island, Vermont, New Hampshire, Maine, Alaska, Hawaii

Lyme Disease Association
Research, Education, Prevention, & Patient support
Lyme Disease Association, Inc.
P.O. Box 1438
Jackson, NJ 08527
t 888.366.6611
f 732.938.7215
lymedir@aol.com
LymeDiseaseAssociation.org

**Lyme Disease Is No Fun:
Let's Get Well!**

Written especially for children
8-12 years old who have Lyme disease.

by
Mary Wall, M.S.Ed., CCLS

edited by
Colleen M. Smith

published by
Lyme Disease Association, Inc.

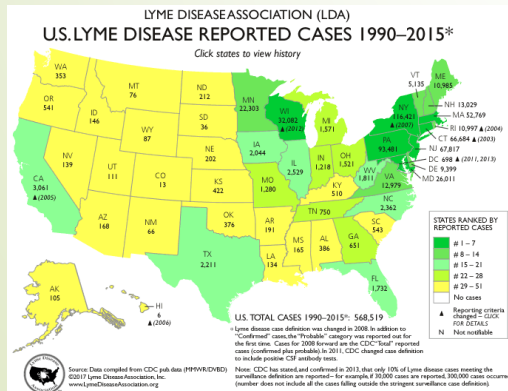
LYME DISEASE ASSOCIATION'S

**Lyme Disease Update:
Science, Policy & Law**

By **Marcus A. Cohen**

Foreword by
Brian Fallon, MD
Columbia University
College of Physicians & Surgeons

Preface by
Amy Tan
NY Times Bestselling Author



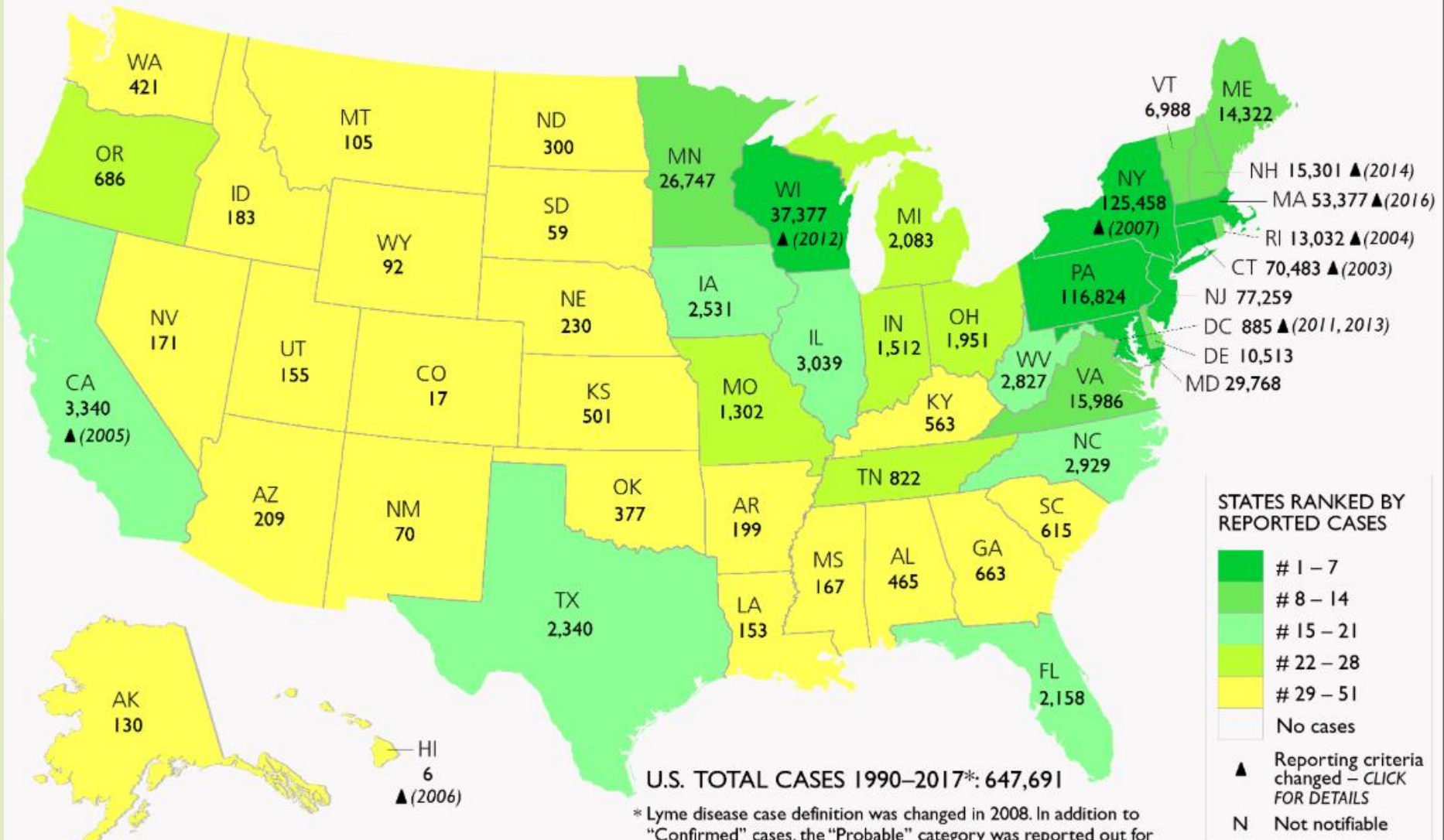
TICKles: Tick Learning & Education for Schools

- LDA Collaborator with (UMDNJ)/Rutgers University
 - Created prevention video
 - TickLES (Tick Learning and Education for Schools) grades 4-8
 - Video will enable children to
 - understand what a tick is
 - recognize a tick attachment (bite)
 - learn what to do if bitten,
 - learn the symptoms of Lyme
 - learn prevention measures
 - Video game, Tick Tackler,* will engage children in learning about ticks
- Under the auspices of EPA grant
 - UMDNJ compiled expert team to develop material & make it kid friendly
 - LDA was a collaborator on the project & hosting the video & game on its website, free to all



LYME DISEASE ASSOCIATION (LDA)

U.S. LYME DISEASE REPORTED CASES 1990–2017*



U.S. TOTAL CASES 1990–2017*: 647,691

* Lyme disease case definition was changed in 2008. In addition to "Confirmed" cases, the "Probable" category was reported out for the first time. Cases for 2008 forward are the CDC "Total" reported cases (confirmed plus probable). In 2011, CDC changed case definition to include positive CSF antibody tests.

STATES RANKED BY REPORTED CASES

- # 1 – 7
- # 8 – 14
- # 15 – 21
- # 22 – 28
- # 29 – 51
- No cases

▲ Reporting criteria changed – [CLICK FOR DETAILS](#)

N Not notifiable



Source: Data compiled from CDC pub. data (MMWR/DVBD)
 ©2018 Lyme Disease Association, Inc.
www.LymeDiseaseAssociation.org

Note: CDC has stated, and confirmed in 2013, that only 10% of Lyme disease cases meeting the surveillance definition are reported – for example, if 30,000 cases are reported, 300,000 cases occurred (number does not include all the cases falling outside the stringent surveillance case definition).

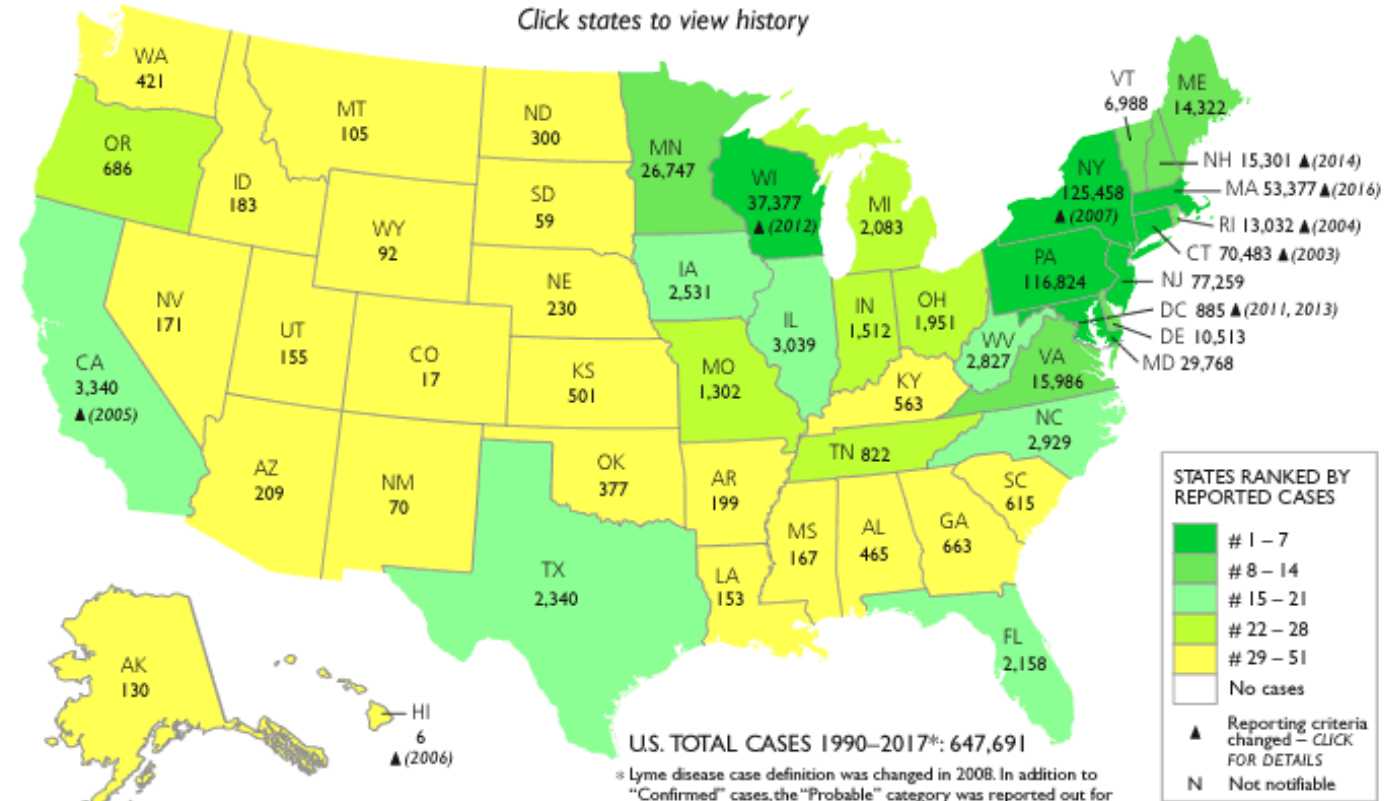
New Jersey (NJ)

2017	5,092
2016	4,350
2015	4,855
2014	3,286
2013	3,766
2012	3,576
2011	4,262
2010	3,712
2009	4,973
2008	3,485
2007	3,134
2006	2,432
2005	3,363
2004	2,698
2003	2,887
2002	2,349
2001	2,020
2000	2,459
1999	1,719
1998	1,911
1997	2,041
1996	2,190
1995	1,703
1994	1,533
1993	786
1992	688
1991	915
1990	1,074
TOTAL	77,259

Close

LYME DISEASE ASSOCIATION (LDA)
U.S. LYME DISEASE REPORTED CASES 1990–2017*

Click states to view history



U.S. TOTAL CASES 1990–2017*: 647,691

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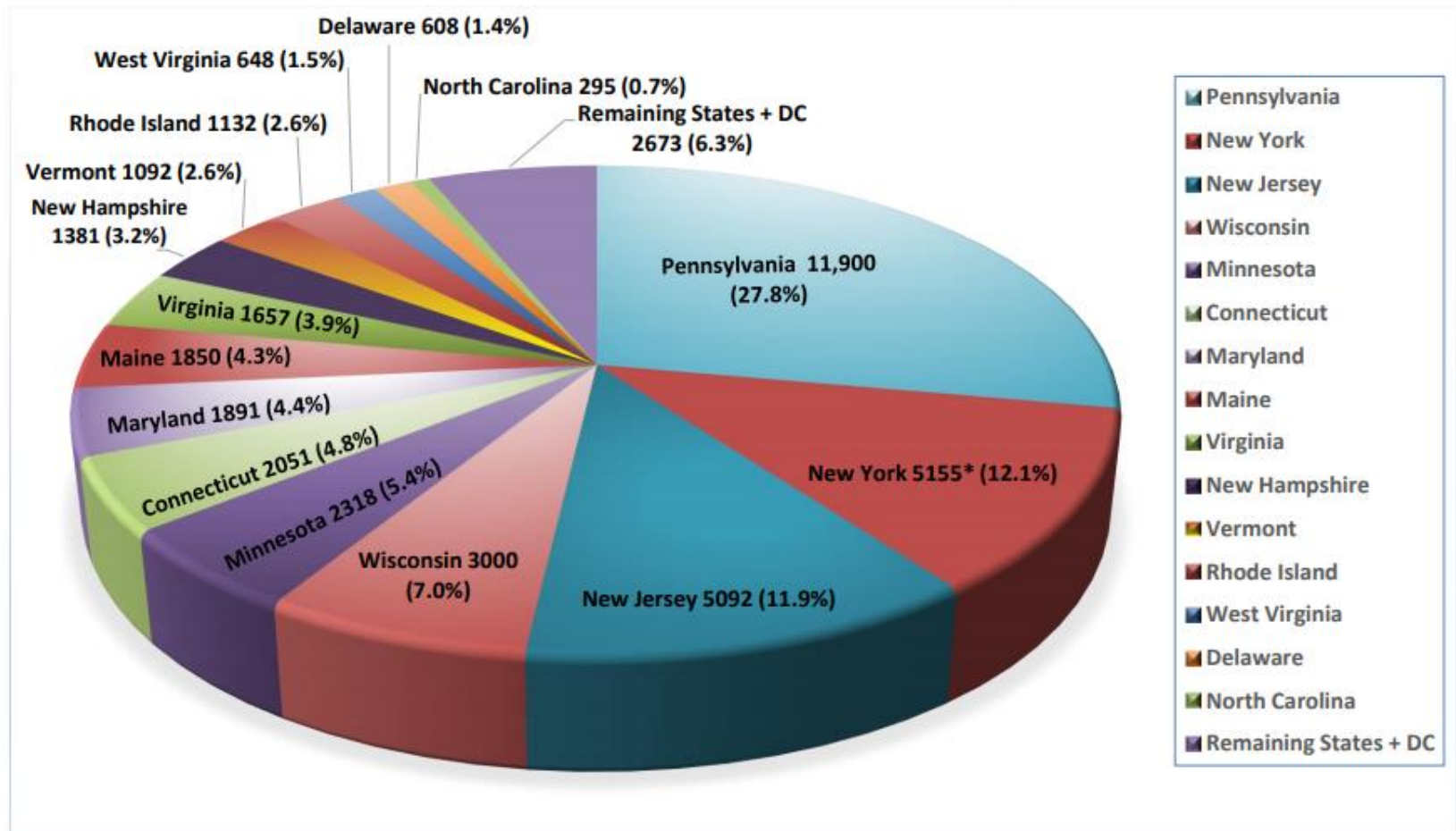


Source: Data compiled from CDC pub data (MMWR/DVBD)
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 www.LymeDiseaseAssociation.org

- NJ 1990-2017 77,259 reported cases in NJ
- 772,590 actual cases per CDC underreporting

Lyme Disease Association Lyme Disease Analysis

2017 US Reported Lyme Disease Cases Featuring Top 15 States



U.S. TOTAL CASES 2017: 42,743

Source data compiled from CDC pub. data (DVBD)

Note1: CDC adopted a change in case definition in 2008. In addition to "Confirmed" cases, the "Probable" category was reported out for the first time

Note2 : CDC has stated, and confirmed in 2013, that only 10% of Lyme disease cases meeting the surveillance definition are reported – for example, if 30,000 cases are reported, 300,000 cases occurred (number does not include all the cases falling outside the stringent surveillance case definition).

Note3: In 2016, MA changed reporting requirements and very few MA cases are now counted by CDC

*In recent years, an increasing number of NY Counties have used estimating to determine Lyme case numbers. The Council of State & Territorial Epidemiologists, in charge of surveillance, doesn't permit estimation to be reported by CDC in the national counts. In 2017, NY State reported it had 9,803 Lyme cases including those 27 estimated county numbers. CDC reported 5,155 Lyme cases for NY state, which excluded the 27 counties estimated numbers.



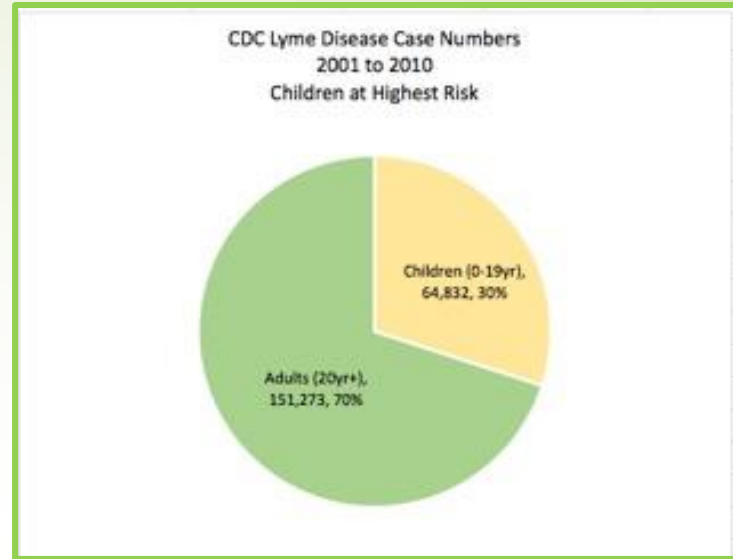
Highest Case # by Age 5-9, 10-14 (2001-2010)



2001-2017 5-9, 10-14 50-54, 55-59

Photos: Pat Smith ©

% Children & Adults 2001-2010



Age Group 0-4 Years 5% of Reported cases (2001-2010)



LDA calculated the percent of children vs. adults



Born & Unborn Affected by Lyme

- Pregnant woman can transmit Lyme to fetus through placenta
- Transplacental transmission
- Can cause birth defects & death of fetus



Lyme Disease Spread: Worldwide Found in more than 80 countries



Current Distribution of *Ixodes ricinus* in Europe as per Vector Net Project



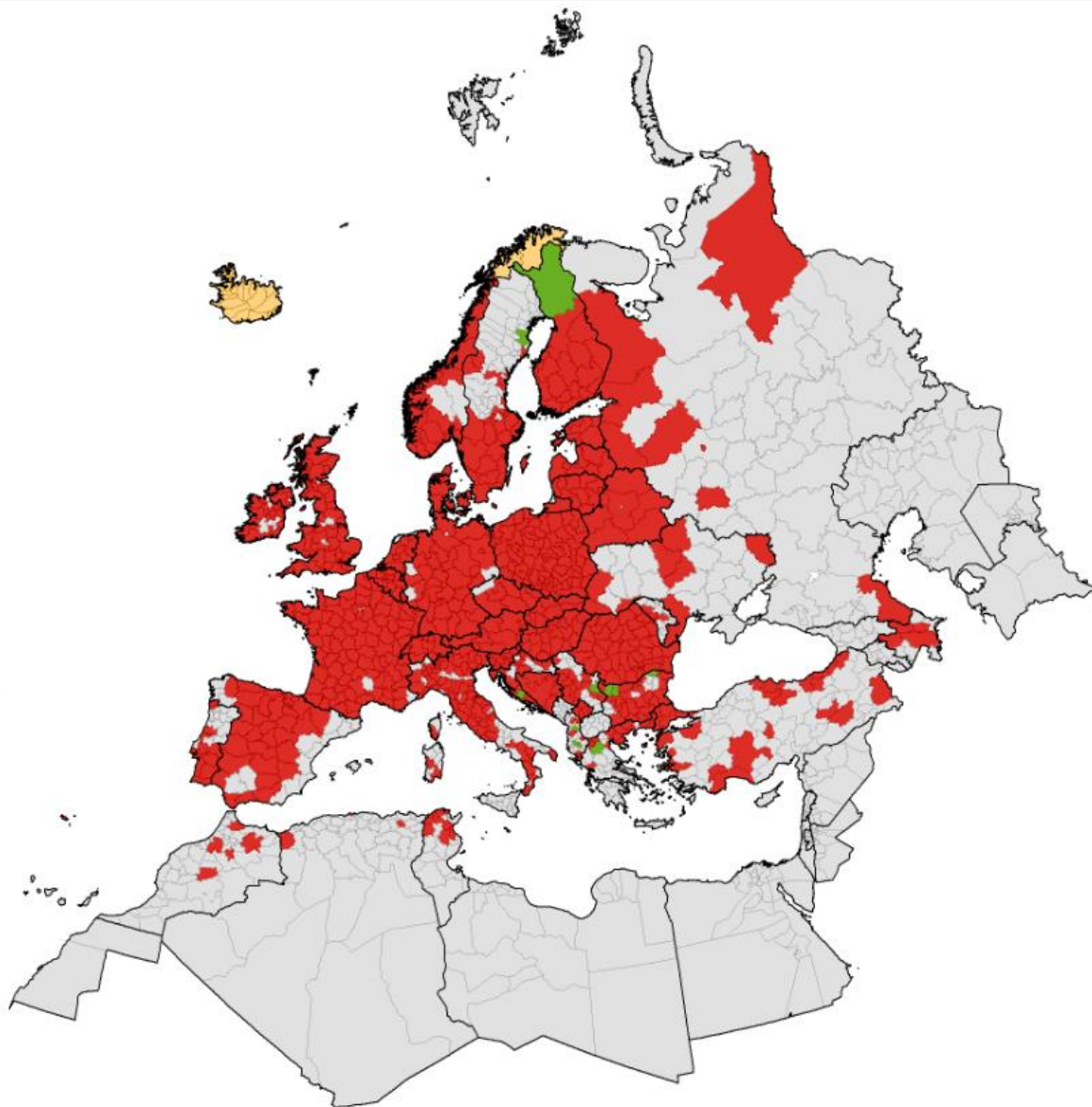
Ixodes ricinus - current known distribution: June 2018

Legend

- Present
- Introduced
- Antic. Absent
- Obs. Absent
- No data
- Unknown

Countries/Regions not viewable in the main map extent*

-  Malta
-  Monaco
-  San Marino
-  Gibraltar
-  Liechtenstein
-  Azores (PT)
-  Canary Islands (ES)
-  Madeira (PT)
-  Jan Mayen (NO)



Iceman Ötzi



© South Tyrol Museum of Archaeology/EURAC/Marco Samadelli-Gregor Staschitz - Terms of Use

- Iceman- preserved~ 5,300 years in ice-may have died 3239-3105 BCE
 - Austrian authorities found 1991, later found to have been in Italy--returned
 - 40+ list of complaints from scientific study
 - “Perhaps most surprising, researchers found the genetic footprint of bacteria known as *Borrelia burgdorferi* in his DNA—making the Iceman the earliest known human infected by the bug that causes Lyme disease.”¹

Used with permission © South Tyrol Museum of Archaeology - www.iceman.it

<http://www.paperdroids.com/wp-content/uploads/2012/06/otzi1.jpg>



Can We Escape Ticks & TBD?



Ixodes uriae

□ Scientists have discovered

- Globally distributed seabird ticks, *Ixodes uriae*³
 - Contain four new viruses, closest relatives found in N. Hemisphere
 - infesting colonies of penguins on the sub-Antarctic Macquarie island
- In Subantarctic- southern hemisphere just north of the Antarctic Circle which contains the Campbell Islands and îles Crozet
 - *Borrelia burgdorferi* transmitted by *Ixodes* ticks which are carried by sea birds
 - Found through DNA analysis in ticks on those islands
 - King penguins on the îles Crozet have antibodies to *B. burgdorferi*.²

¹ This research was funded by the Australian Antarctic Division. WENDY PYPER Corporate Communications, AAD
<http://www.antarctica.gov.au/about-us/publications/australian-antarctic-magazine/2006-2010/issue-16-2009/science/sub-Antarctic-penguins-infected-with-tick-borne-viruses>

² "Encyclopedia of the Antarctic Vol.1" (ed: B. Riffenburg, 2007 p.335), Ticks Tick Borne Dis. 2014 Oct;5(6):939-42. doi: 10.1016/j.ttbdis.2014.07.013. Epub 2014 Aug 20.
First detection of *Borrelia burgdorferi* sensu lato DNA in king penguins (*Aptenodytes patagonicus halli*). Schramm F1, Gauthier-Clerc M2, Fournier JC3 et al ³ Photo thanks James Occi PhD (cand.) Seabird tick M,F



Penguin Rookery on Macquarie Island between New Zealand & Antarctica



Photo thanks Jenny Fraser, MH nurse, Royal Perth Hospital



Australian Snake with Ticks 2019



Python with 511 ticks *Ixodes holocyclus* (paralysis tick)

Moose Studies (Ghost Moose)



- ❑ 2001 began 5 year study NH
 - Avg. moose: 35,000 ticks--can have 160,000, (50/1in.²)
 - *Dermacentor albipictus* (winter or moose tick)
 - Ticks suck out so much blood
 - Leave moose anemic and emaciated, unable to survive winter.
 - Moose rub on trees/ scrape away dark winter coats called "ghost moose"
1992–20% N.H.'s moose: some hair scraped off due to ticks. Now ~100%

- ❑ University of New Hampshire/3 state study Maine, NH, VT¹
 - ME & NH teams recently captured/collared 123 moose
 - VT plans to capture 60 moose
 - NH moose pop. Est 4,000 down from 7,500 in early 2000s
 - VT down to 2,200 from high of 5,000 in 2006 (hunting some)
 - ME pop. in 2012 76,000 moose, current estimate 60,000-70,000 (2017)
 - Ticks killing 70% of moose calves in ME & NH
 - 2015 75% of moose calves tracked in NH & 60 % in ME died²
 - Winter 2016 - 80% collared calves died (Yankee magazine March/April 2017)
 - 2017 50% of moose calves survived western ME (2016 ¾ died)(Kantar: state moose biologist)

- ❑ VT calf mortality rate 40% in 2017, primarily due to winter ticks; 52% 2018 ³



Ear of NJ Black Bear



Partially engorged
female blacklegged ticks
feeding on black bears (NJ)

86 ticks from 17 black bears collected
in Louisiana. 2 had Bb *PMC 2-15-13*



Female tick turned over,
male mating

James Occi, MA, MS, Rutgers,
Lyme Disease Association Scientific &
Professional Advisory Board Member





USDA **Patrolling the
Rio Grande
for stray “ticky
livestock, exotic
livestock and deer.**



**Strays are captured,
“scratched” for ticks,
treated, and returned
to Mexican owners for
the cost of feed.**





This form not intended for shipment of livestock.
TEXAS ANIMAL HEALTH COMMISSION

Final 73226

14 DAY PERMIT

Mr Carla Everett

County Dimit

Premises Everett Ranch

To trail or haul (5) Equine Bovine

DESCRIPTION (3) Paint Geldings

(1) Bay Gelding

(1) Black Gelding

TICKICIDE AND TEST COHAI

AGREEMENT: I understand that the 14-day pass procedure is a cooperating individuals only. Livestock on 14-

**Horses moved out
inspected, sprayed
and permitted....**

“14-day pass” allowed



**Cattle are inspected, then
run thru spray boxes or
submerged in dipping vats
charged with Co-Ral**

Fever Ticks Infecting Cattle at Border



TAHC

➤ Ticks

- Cattle tick- *Rhipicephalus annulatus* (formerly *Boophilus*)
- Southern cattle tick- *Rhipicephalus microplus*
 - Transmit parasite that causes *Babesia bovis* or *Babesia bigemina*

➤ Symptoms

- Destroy red blood cells
- Can result in death for up to 90% of susceptible naive cattle

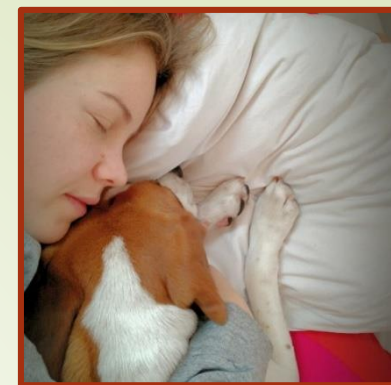
➤ Results

- According to Texas Animal Health Commission
 - 2,655 premises, totaling 950,500 acres, under quarantine in Texas due to fever ticks
 - Ranchers along the U.S.-Mexico border say the disease they carry has devastated their operations. Some have let ranches idle, cost prohibitive to run cattle
 - Portions of eight South Texas counties have established fever tick quarantines. The counties include, Cameron, Live Oak, Kinney, Maverick, Starr, Webb, Willacy, Zapata

➤ Treatment

- no cure or vaccine

Dogs, Cats & Lyme



- Dogs act as sentinels of Lyme disease
 - often diagnosed with Lyme before people/50% more likely
 - tend to roll in leaves, run unchecked into tick habitats
 - can bring unattached ticks into home
 - IDEXX Ref. Labs database 6-13-15 thru 1-17-17 retrospective study in Bb & Ehrlichia areas, 846,626 canine chemistry/urinalysis
 - statistically significant association between tick-borne disease and CKD
 - had 43% > risk of developing kidney disease when Borrelia antibodies were present;
 - 300% > risk of developing kidney disease when Ehrlichia antibodies were present
 - Other dog tick-borne Diseases
 - Ehrlichiosis & anaplasmosis
- There is a vaccine for dogs
 - 2 sides- give to dogs or not M. Littman et al; Today's Veterinary Practice
 - "In the Banfield study of 1.2 million vaccinated dogs, the Lyme disease vaccine (monovalent bacterin), when used alone, produced more postvaccinal adverse events within 3 days than any other canine vaccine."
- Cats get less Lyme, can also get ehrlichiosis & anaplasmosis
 - can bring in unattached ticks
- 2017 published in Jones, EH et al, Zoonoses & Public Health
 - 2727 households in CT, MD, NY
 - 50% owned dog, cat or both; 88% used pet tick control
 - 31% of households with pets found tick on a human-- 1.83x the risk;
 - 1.49x risk of finding ticks attached to humans

Canine Lyme Disease 2017 / Companion Animal Parasite Council

STATE	# TESTED	# POSITIVE	% POSITIVE	#/#
Pennsylvania	340,409	47,678	14.01	1/8
New Jersey	165,589	17,201	10.30	1/10
New York	346,281	38,266	11.05	1/10
Wisconsin	172,288	14,813	8.6	1/12
Minnesota	144,128	12,175	8.45	1/12
Maryland	183,936	12,726	6.92	1/15
Connecticut	143,986	23,566	16.37	1/7
Maine	89,545	12,674	14.15	1/8
Virginia	290,577	22,786	7.84	1/13
Rhode Island	23,279	2,981	12.81	1/8
New Hampshire	10,754	1,415	13.16	1/8
Vermont	34,422	5,000	14.53	1/7
Delaware	31,247	1,715	5.49	1/19
West Virginia	37,381	3,094	8.28	1/13
North Carolina	271,909	6,237	2.29	1/44

*Data: IDEXX
Represents < 30%
activity in
geographic
region*





Love Those Oposums!



Rick Osfelt-Carey Institute, NY: Opossum can kill about 5,000 ticks a season
More than 90% of ticks picked up by it are swallowed and killed

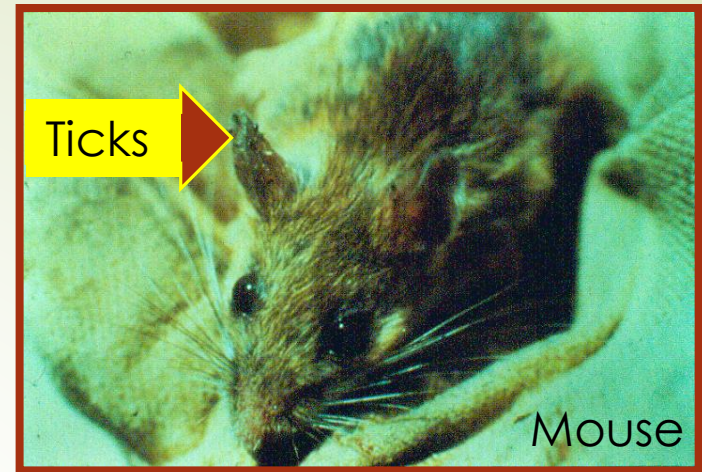


Significant Players in Lyme

Harbor diseases: Reservoir hosts

East

- White-footed mouse
- Vole
- Chipmunk
- Eastern gray squirrel
- Shrew
- Other small mammals
- Some birds (e.g., robin)



West Coast

- Western gray squirrel
- Wood rat
- American robins, dark-eyed juncos, golden-crowned sparrows



South

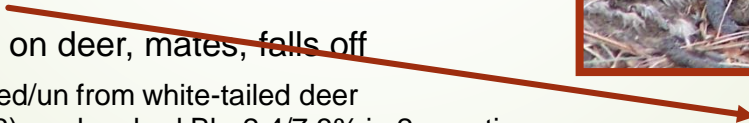
- Cotton mouse
- Cotton rat
- Lizards

Transport & meal: Deer¹

Female tick often feeds last on deer, mates, falls off

- Hudson Valley, NY attached/un from white-tailed deer
- Study: None attached (148) on deer had Bb, 2.4/7.3% in 2 counties
- had Bb, mechanism in deer may clear Bb from attached ticks—compared to ticks on vegetation

¹Med Vet Entomol. 2017 Mar;31(1):1-5. doi: 10.1111/mve.12191. Epub 2016 Oct 4. Impact of white-tailed deer on the spread of Borrelia burgdorferi. Roome A1,2, Hill L1,2,3, Al-Feghali V1,4 et al



Vectors: Ticks

- Transmit disease



How Do Ticks Get on Us?

☐ Hard-bodied ticks

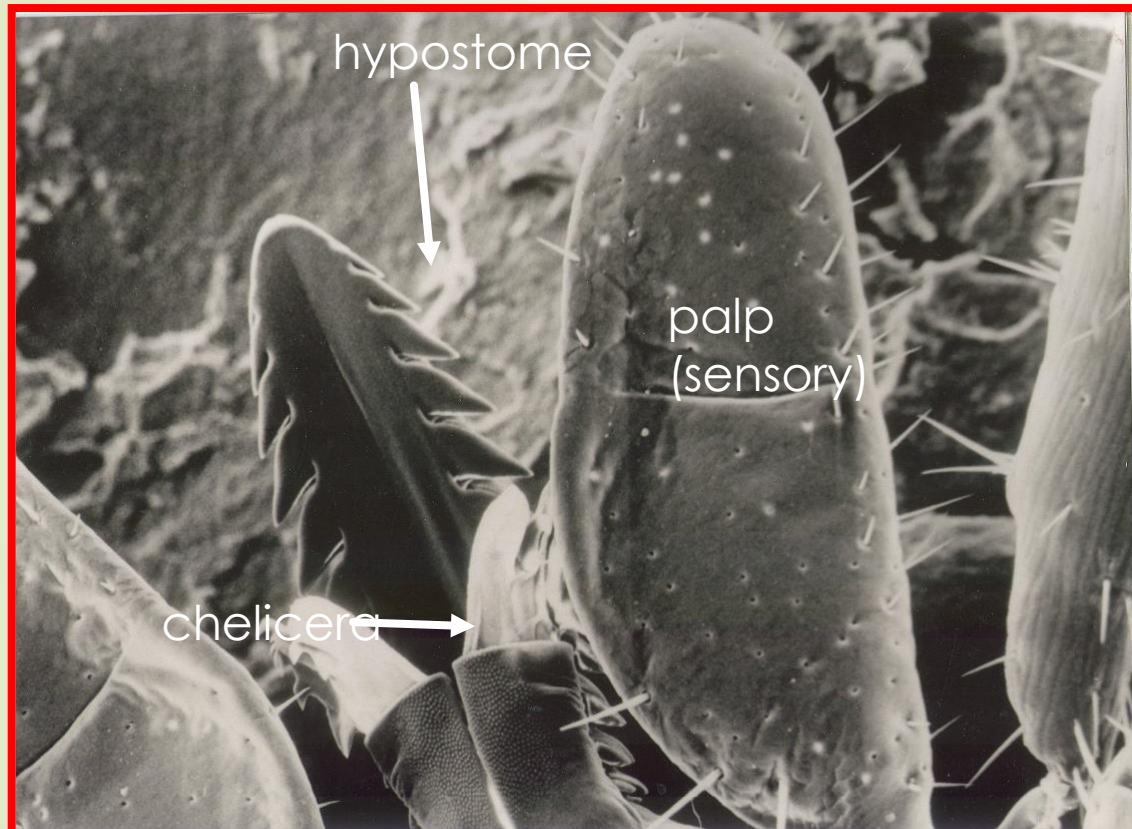
- Deer & American Dog
 - ticks climb small plants, grass
 - Questing: animals brush grass, tick latches on
 - Passive feeder
- Lone star ticks will run after you
 - Active feeder
- If you have contact with leaves/ground cover, ticks climb up on you
- Pets carry them to people

☐ Soft-bodied ticks

- Ornithodoros ticks
 - Hide in animal burrows
 - Found in old cabins



How a Tick Feeds



Secretes something to numb you

Cuts you open (chelicera)

Sticks hollow straw-like
barbed hypostome in you

Secrets glue-like substance
into you to cement itself to you

Sucks your blood

Sometimes secretes blood
thinners & immune regulators
into you

During feeding, organisms in
tick flow inside you

Tick Attachment Time & Lyme Transmission

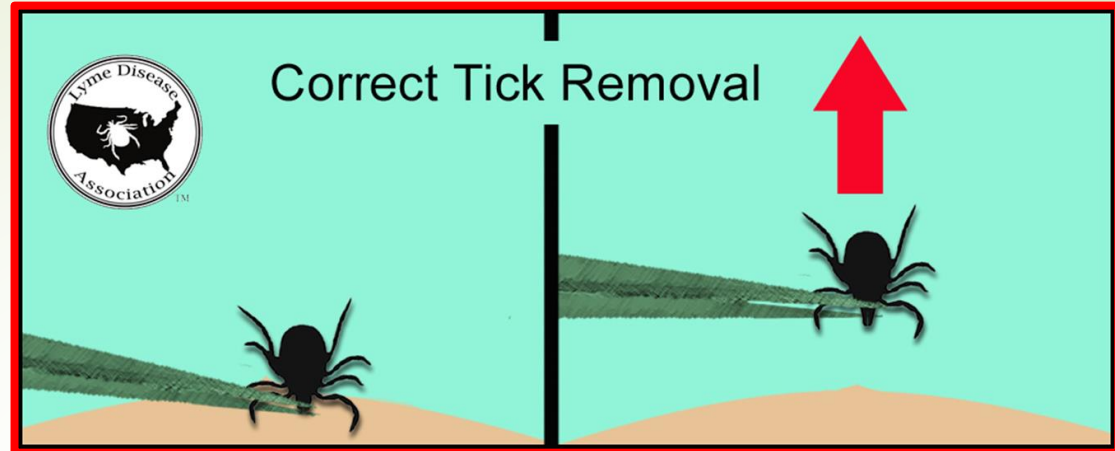


- ❑ Longer a tick attachment, greater the risk of infection
 - Why days of attachment used as necessary for transmission
 - Generally Lyme bacteria (*Borrelia burgdorferi*) in tick midgut
 - Some say takes ~24-48+ hours to migrate to salivary glands
 - This is why some say 24-48 hours tick attachment necessary
 - **Not always true!** ^{1,2}
 - Sometimes, bacteria already systemic & in salivary glands at time of attachment
 - “the possibility that transmission of Lyme disease spirochetes could occur within 24 hours of nymphal attachment under unusual circumstances should not be discounted...Partially fed ticks able to re-attach could result from detachment from dead animals or possibly by host grooming.”¹
- ❑ Other TBDs can be transmitted in very short time period (e.g. Powassan)

¹Eisen L (CDC) Pathogen transmission in relation to duration of attachment by Ixodes scapularis ticks. Ticks & Tick Borne Dis. 2018 Mar;9(3):535-542. doi: 10.1016/j.ttbdis.2018.01.002. Epub 2018 Jan 31.

² Cook M. Lyme borreliosis: a review of data on transmission time after tick attachment Int J Gen Med. 2015; 8: 1–8. Published online 2014 Dec 19. doi: 10.2147/IJGM.S73791

Proper Tick Removal



- Do not
 - put anything on tick
 - burn the tick
 - touch the tick with fingers
 - squeeze the tick
- Do use pointed tweezers*, close to skin on “head” of tick *(or special tick removal tool)
 - pull straight out, do not twist or squeeze
- Clean skin area with antiseptic afterwards
- You can save the tick for testing at testing labs*/ doc
 - save preferably live in Ziploc bag with moist cotton ball
 - for testing labs, call health department, or see www.LymeDiseaseAssociation.org
- Call your doctor
- Stick tick in tape for permanent disposal

Lyme Rashes



- ❑ Not everybody gets one!
- ❑ Can look different than classic bull's eye¹
- ❑ Can be on other places on your body than the bite site (disseminated disease)

¹Forrester JD, Meiman J, Mullins J, et al. Update on Lyme carditis, groups at high risk, and frequency of associated sudden cardiac death—United States. *MMWR* 2014; 63 (43): 982-983.

Ann Intern Med 2002; Mar 19;136(6):421-8 Clinical characteristics and treatment outcome of early Lyme disease in patients with microbiologically confirmed erythema migrans. Smith RP, Schoen RT, Rahn DW, Sikand VK, Nowakowski J, Parenti DL, Holman MS, Persing DH, Steere AC. Maine Medical Center Research Institute, Lyme Disease Research Laboratory, 13 Charles Street, Third Floor, Portland, ME



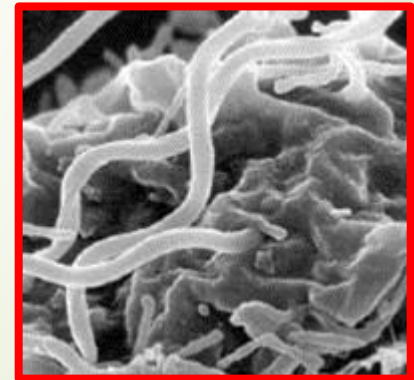
Typical & Atypical Images of the Lyme Rash (erythema migrans)



Photos courtesy of the Lyme & Tick Borne Diseases Research Center at Columbia University and Brian Fallon, MD, John Aucott, MD, Steven Schutzer, MD, Elisabeth Aberer, MD and Andrea Gaito, MD. www.columbia-lyme.org
Poster creation supported by Grant from the Lyme Disease Association, Inc. <http://www.LymeDiseaseAssociation.org>

Columbia University
Rash Poster

Can download
from LDA website



Borrelia burgdorferi
Courtesy Dave Dorward, PhD



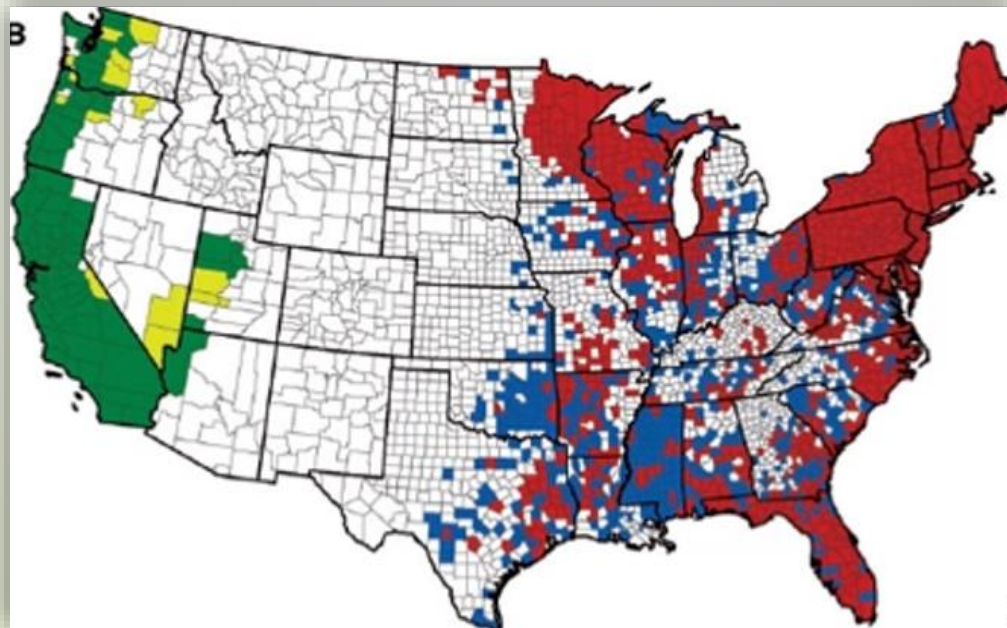
Lyme Disease Tick Map 2015



Ixodes pacificus (green & yellow map)



Ixodes scapularis (red & blue map)

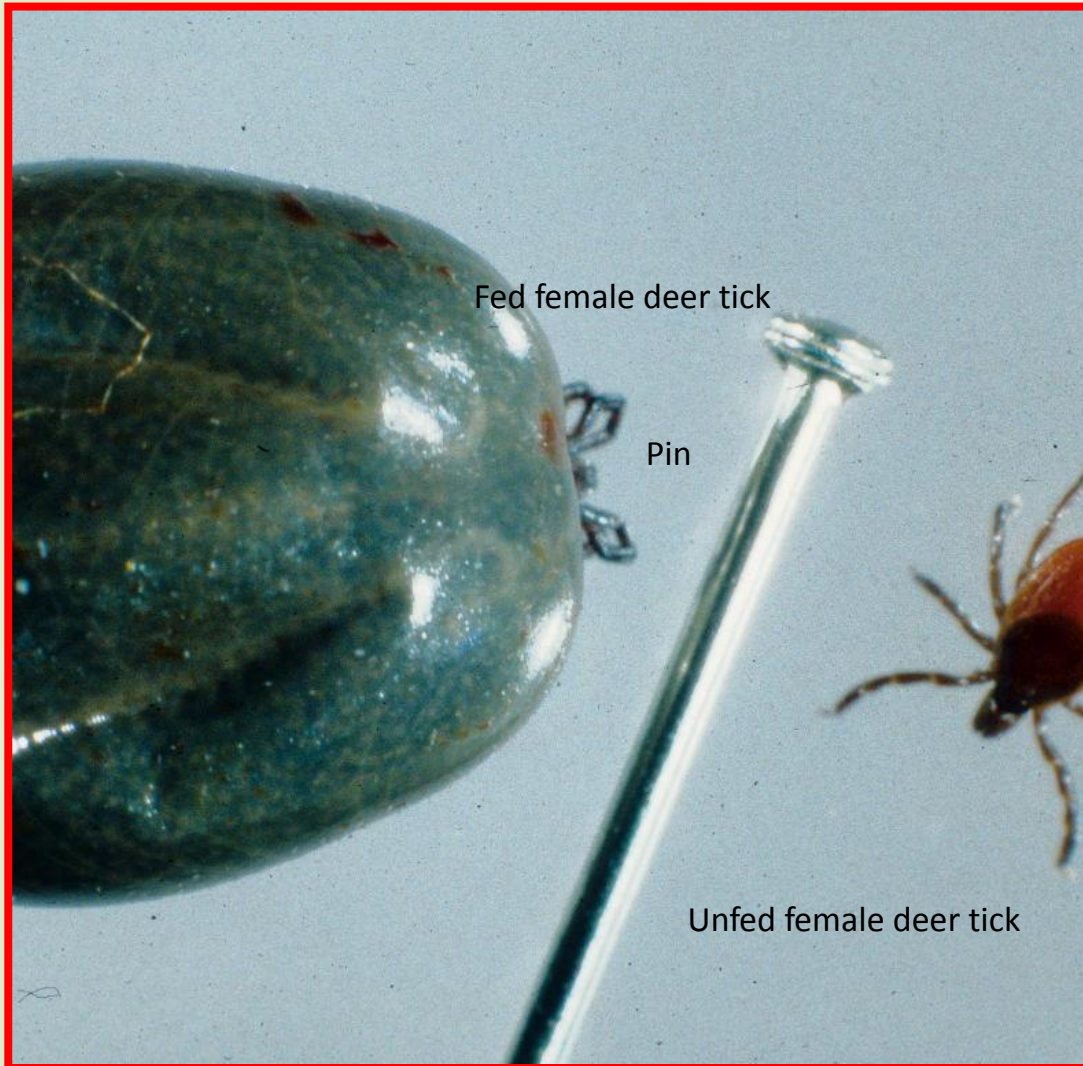


2015
I. Pacificus
3.6% of counties

2015
I. Scapularis
45.7% of counties

2015 Total 49.3% of counties/43 states

Deer Tick *Ixodes Scapularis*



Transmits

Borrelia burgdorferi (Lyme)

Borrelia mayonii (Lyme)

Borrelia miyamotoi (Lyme-like)

anaplasmosis

babesiosis

bartonellosis

ehrlichiosis

Powassan virus

tick paralysis (toxin-tick removal)

tularemia

Deer Tick Laying Eggs (Ovipositing)

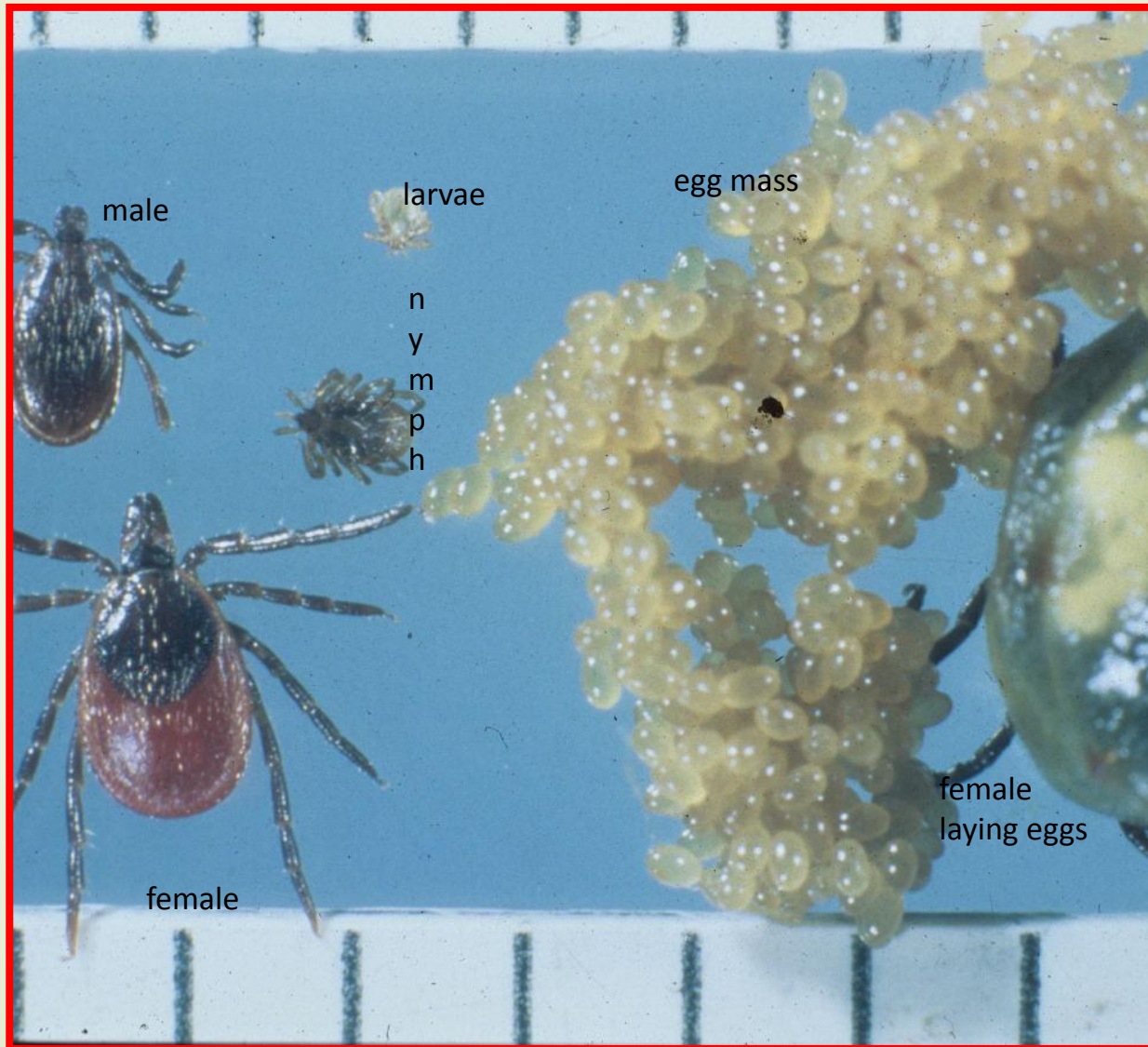


Photo: James L. Occi, MA, MS/ LDA Professional Advisory Board



Deer Tick Stages

eggs, larvae, nymph, adult



Deer Ticks & Poppy Seeds

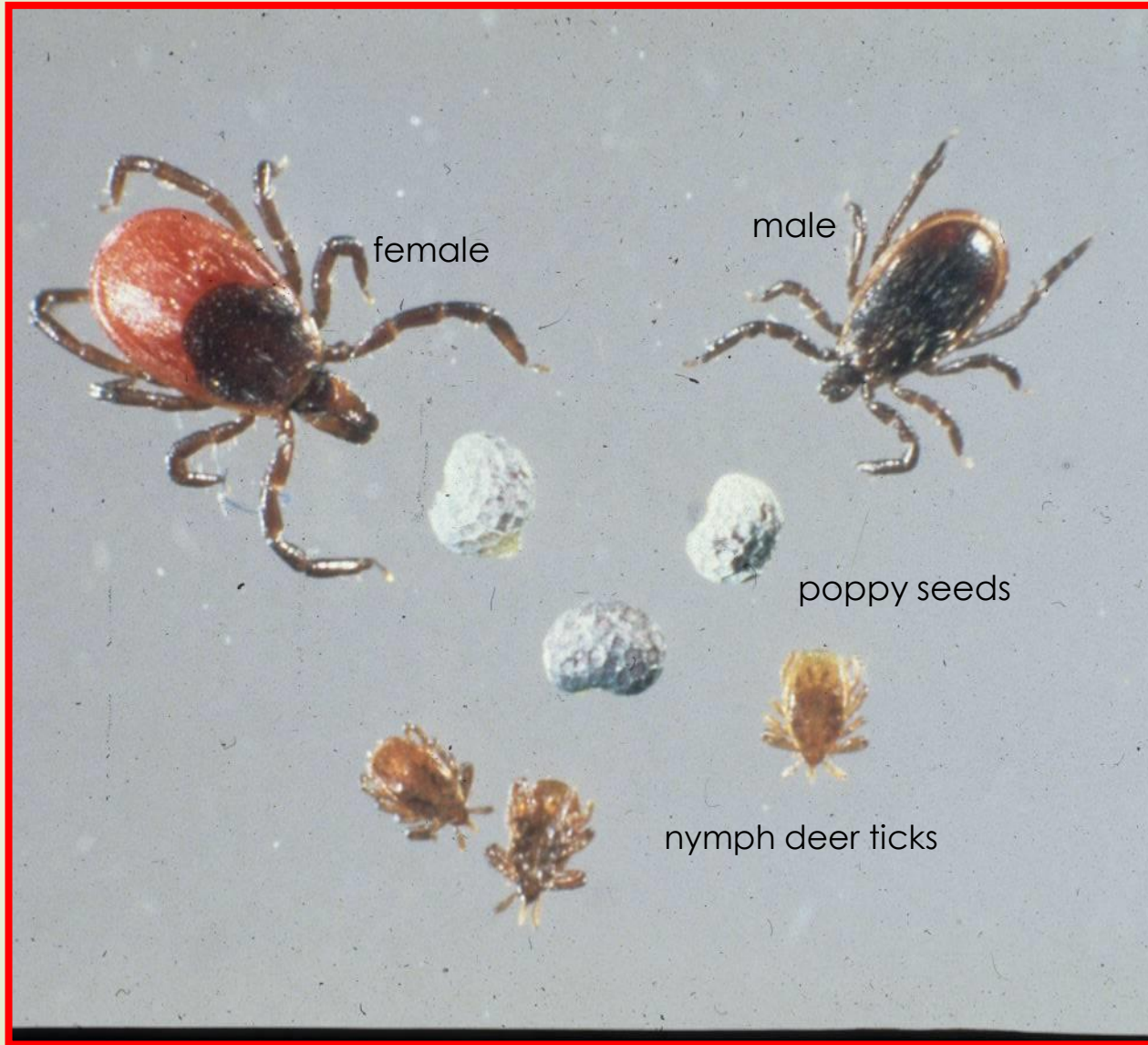


Photo thanks: Female Deer tick, James L. Occi, MS, MA LDA Professional Advisory Board



American Dog Tick & Deer Ticks

Size difference on paper clip



Photo Thanks James Occi, MS, MA LDA Professional Advisory Board



Western blacklegged tick *Ixodes pacificus*



Transmits

B. burgdorferi

B. miyamotoi

A. phagocytophilum

Co-Infections: What Does That Mean?

- One tick bite can cause > one disease
 - Co-Infection
 - Deer ticks carry/transmit
 - *Borrelia burgdorferi* or *Borrelia mayonii* (Lyme)
 - Babesia
 - Anaplasma
 - *Ehrlichia*
 - *Bartonella*
 - *Tularemia*
 - *Borrelia miyamotoi*
 - Powassan virus
 - tick paralysis toxin
 - Other tick-borne diseases
 - May have similar symptoms as Lyme disease
 - May have different treatments



Disease	Ticks	Region	Test	Treatmt	Notes
Lyme	Ixodes scapularis	NE, S, <u>MidW</u>	Yes	Yes	B.burgdorferi B.mayonii (cur. Lyme test)
Lyme	Ixodes pacificus	W. Coast stat.	Yes	Yes	B.burgdorferi
Babesiosis	Ixodes scapularis Ixodes pacificus	Thru US	Yes	Yes	Blood transfusion
Anaplasmosis	Ixodes scapularis Ixodes pacificus	Many areas of US	Yes	Yes	
Ehrlichiosis	Ixodes scapularis Amblyomma americanum		Yes	Yes	
Bartonellosis*	Ixodes scapularis Ixodes pacificus	Thru US	Yes	Yes	<u>CDC</u> :not yet + on tick transmission
Borrelia miyamotoi	Ixodes scapularis Ixodes pacificus	NE, Mat, <u>UMid</u>	Yes	Yes	Related to relapsing fever
Tularemia	Ixodes scapularis Amblyomma americanum Dermacentor variabilis Dermacentor andersoni		?	Yes	CDC: No Rapid dx tests Contaminated dust, H2O, bioterror
Powassan	Ixodes scapularis	<u>N/SE, Mat, MW</u>	Yes	No	<u>Transm</u> minutes
Tick paralysis	Ixodes scapularis Dermacentor variabilis Amblyomma americanum		No	Yes	Remove tick
Colorado tick fever	Dermacentor andersoni Dermacentor variabilis	Far West	Yes	No	
Q fever	Amblyomma americanum Dermacentor andersoni		Yes	Yes	
Rickettsia parkeri	Amblyomma maculatum	Gulf coast	?	Yes	<u>Rickettsial</u> tests
Rickettsia 364D (philipii)	Dermacentor occidentalis	California	?	Yes	CDC:RMSF test
Rocky Mt. SF	Dermacentor andersoni Dermacentor variabilis	Much of US	Yes	Yes	Hi fatality rate Amblyomma am
Heartland virus	Amblyomma americanum	10 MW to S <u>st</u>	No	No	40 cases to date
Bourbon virus	Amblyomma americanum	KS, OK, MO	No	No	~6 cases
STARI	Amblyomma americanum	NE, SE, <u>MdW</u>	No	Yes	No known cause
Alpha-gal allergy	Amblyomma americanum	E, scattered elsewhere	Yes	?	No red meat/products
Tick-Borne relapsing fever	Ornithodoros	Western US, >altitudes	Yes	Yes	Also louse-borne

20 US tick-borne diseases/conditions



Deer tick *Ixodes scapularis*

- ❑ One tick bite can transmit more than one disease
 - Deer ticks transmit
 - *Borrelia burgdorferi* or *Borrelia mayonii*--Lyme
 - Babesia
 - Anaplasma
 - *Ehrlichia*
 - *Tularemia*
 - *Borrelia miyamotoi*
 - *Powassan virus*
 - tick paralysis toxin
 - *Bartonella* *



➤ * tick transmission still under investigation

Photo thanks to the late Ed Masters, MD



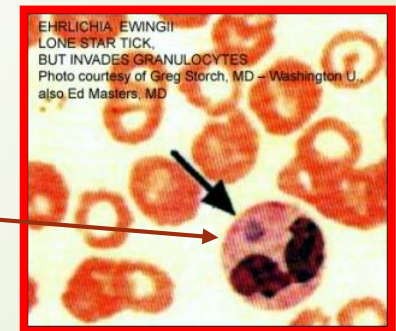
Anaplasmosis & Ehrlichiosis

□ Anaplasmosis (HGA), formerly Ehrlichiosis (HGE)

- Carried by the deer tick, western blacklegged tick
- Symptoms
 - Onset of anaplasmosis generally begins within a week of a tick bite
 - Often includes fever, severe headaches, malaise, muscle pains, chills, death can result. More severe symptoms if co-infected with Lyme, Rashes rare, May include confusion, hemorrhages, and renal failure
- Tests
 - Blood smears, IFA (IgM & IgG) and PCR. Rec: use >1 type of test
- Treatment
 - Doxycycline

□ Ehrlichiosis

- Caused by *Ehrlichia chafeensis* bacteria
 - Transmitted by the lone star tick
- Caused by *E. ewingii*
 - Transmitted by lone star tick
- Caused by *Ehrlichia muris-like*
 - Transmitted by deer tick (blacklegged)
- Tests
 - Blood smears, IFA (Immuno-Fluorescent Assay), PCR for HME
- Treatment
 - Doxycycline



Babesiosis



- ❑ One of most common co-infections w/ Lyme
- ❑ Can be transmitted through blood supply
- ❑ FDA finally approved test to screen for *Babesia microti*, main species in US to cause infection 3-6-18
- ❑ FDA approved screen test for Babesia microti, B. duncani, B. Divergans, B. venatorum 2-07-19

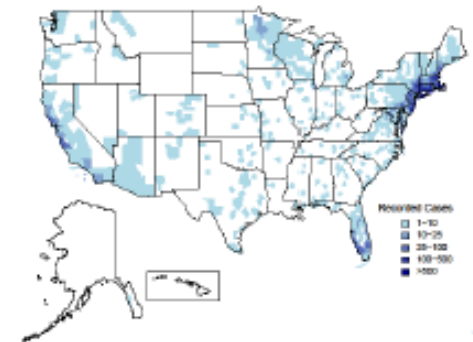


FDA U.S. Food and Drug Administration
Protecting and Promoting Public Health

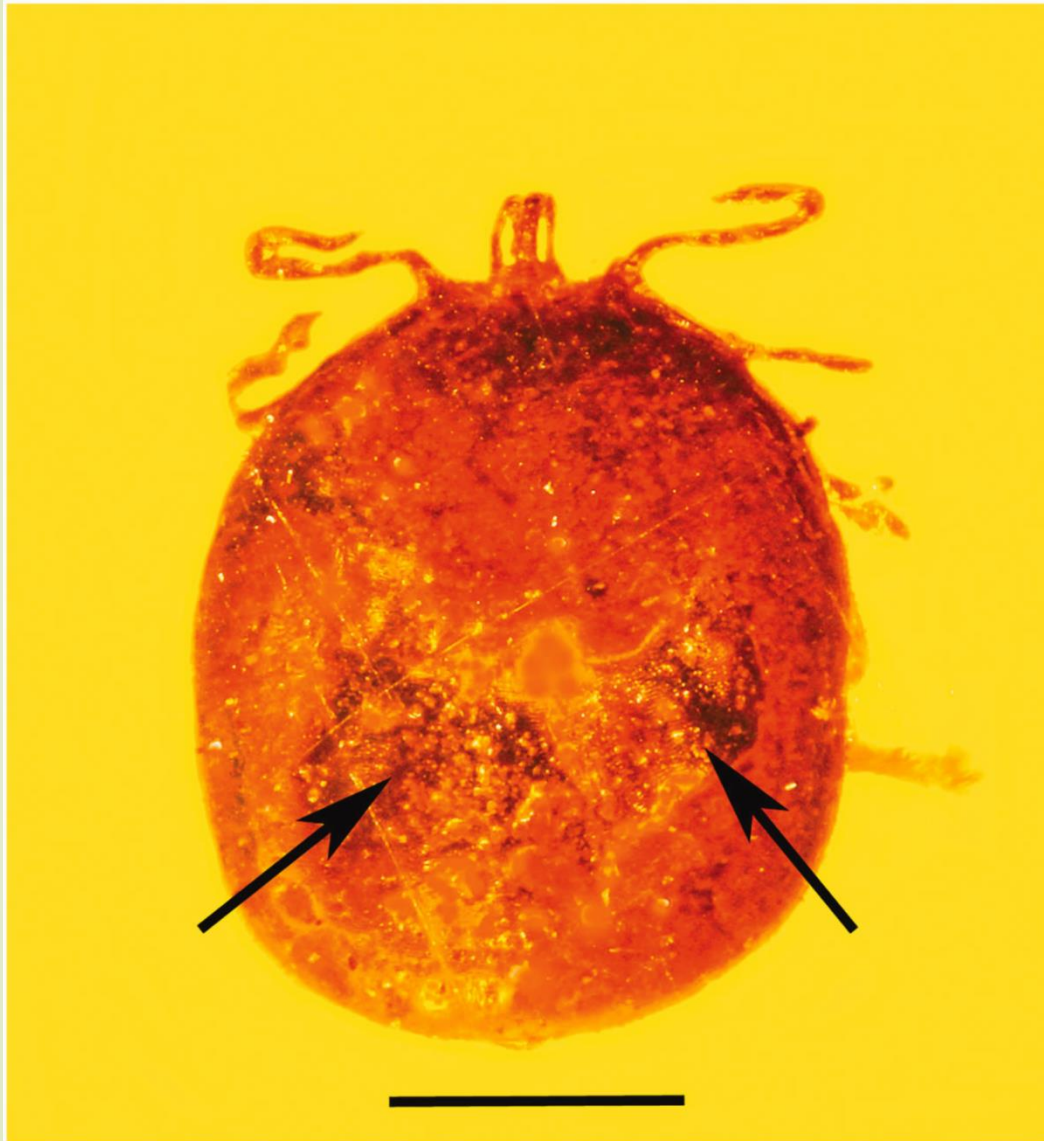
www.fda.gov

Nationwide Prevalence of Babesiosis (CMS)

- 2006-2013
 - 10,301 unique diagnoses of babesiosis
- Cases reported from all states and Washington D.C., except Wyoming



Engorged Nymphal *Amblyomma* Tick



.9mm

- Found in Dominican Republic
- Tick in amber (fossilized tree resin)
- 15-45 million years old
- Arrows show where tick was forcibly removed off animal, Probably a monkey
- Surrounded by erythrocytes
- Contains developing stages of a piroplasm resembling Babesiidae family was found preserved (*Babesia*)
- Amber was then cracked open & tissue inside tick was removed

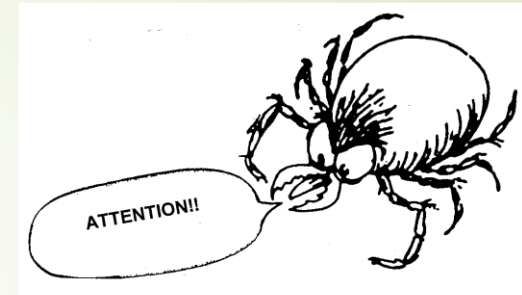
Poinar, G Jr; Fossilized Mammalian Erythrocytes Associated With a Tick Reveal Ancient Piroplasm
J Med Entomol tjw247; 3/20/17
<https://doi.org/10.1093/jme/tjw247>

Photo used with permission from
George Poinar, Jr Oregon State University

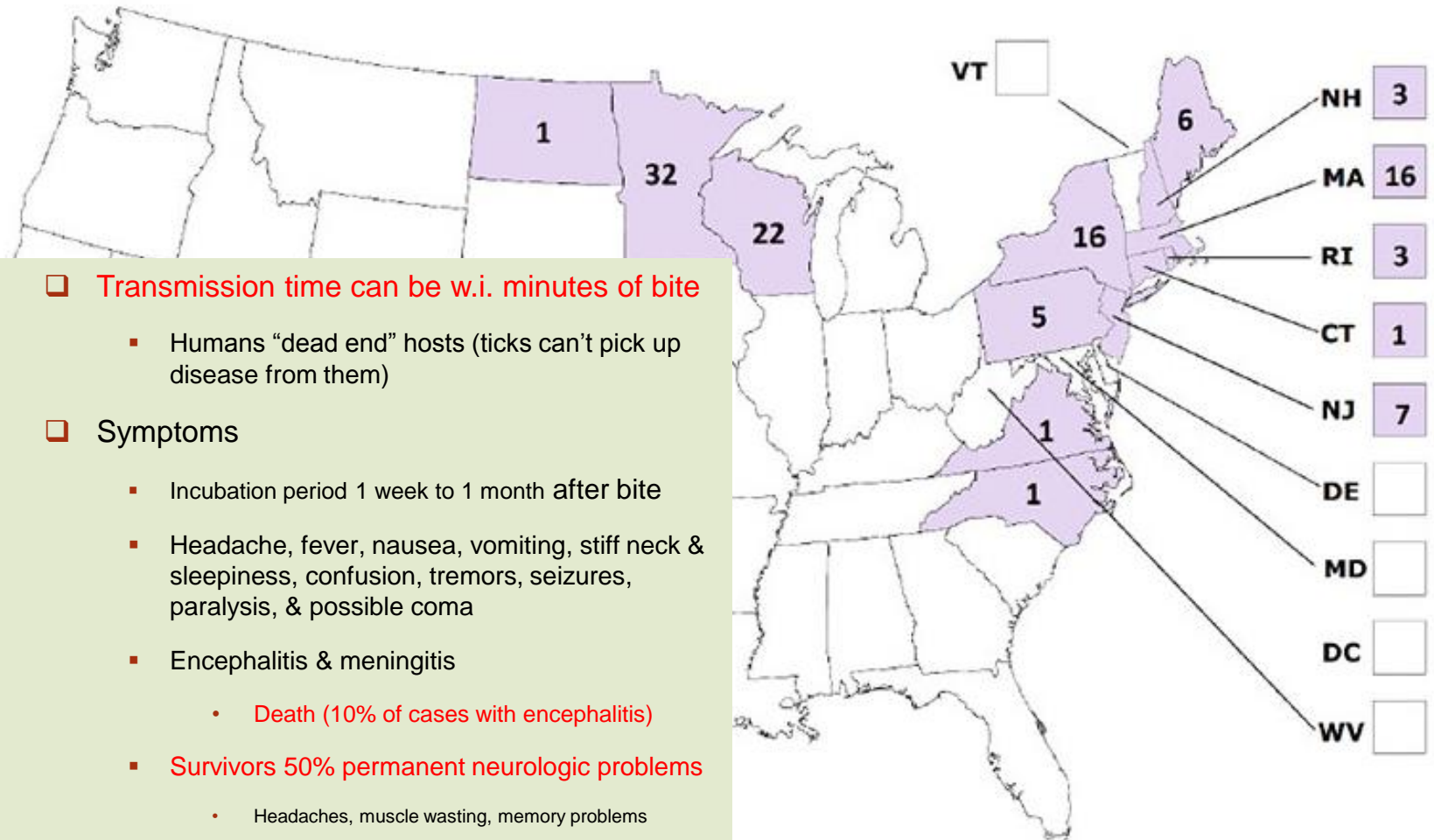


Borrelia miyamotoi-Lymelike disease

- ❑ Spirochete-shaped bacteria closely related to relapsing fever group of *Borrelia*
 - More distantly related to *Borrelia burgdorferi*
- ❑ Transmitted by:
 - black legged ticks (“deer ticks”) *I. scapularis*
 - western blacklegged ticks *I. pacificus*
- ❑ Produces Lyme-like illness
 - fever, headaches, muscle aches, chills, joint pain, fatigue, rash uncommon
- ❑ Study human blood samples 5/13 – 10/14
 - 11,515 tested/ 97 + by PCR Molloy et al 2015
- ❑ PCR testing, e.g. labs
 - Imugen- whole blood PCR (Div. of Oxford Immunotech Inc)
 - Mayo Clinic- PCR whole Blood (BMIYB)
 - Quest- DNA Real Time PCR
 - Igenex
- ❑ Treatment: doxycycline
 - Amoxicillin & ceftriaxone have also been used (CDC)



CDC Powassan Virus Neuroinvasive Disease 2008-2017



❑ Transmission time can be w.i. minutes of bite

- Humans “dead end” hosts (ticks can’t pick up disease from them)

❑ Symptoms

- Incubation period 1 week to 1 month after bite
- Headache, fever, nausea, vomiting, stiff neck & sleepiness, confusion, tremors, seizures, paralysis, & possible coma
- Encephalitis & meningitis
 - Death (10% of cases with encephalitis)
- Survivors 50% permanent neurologic problems
 - Headaches, muscle wasting, memory problems

❑ Treatment

- Supportive only available treatment

❑ Commercial test available as of 2017

Bartonellosis



□ Bartonella sp. illness (bacteria)

- Transmitted by flea, cat scratch, lice
 - May be transmitted by *Ixodes scapularis* (blacklegged or deer tick)
- 2004 study in NJ
 - PCR of IS ticks in NJ: Bb 33.6%, Bm 8.4%, Ap 1.9%, *Bartonella spp* 34.5% ²
- CDC position “ Ticks may carry some species of *Bartonella* bacteria, but there is currently no causal evidence that ticks can transmit *Bartonella* infection to people through their bites.”
- Symptoms
 - When present in combination with Lyme, atypical presentations may result including visual problems, headaches, significant lymph node enlargement, resistant neurological deficits, & new onset seizure disorder
- Tests
 - Diagnosis- acute & convalescent antibody titers (IFA) and/or PCR (some labs can only ID *B.henselae*)
- Treatments
 - Cefotaxime sodium & ceftriaxome sodium, doxy, azithromycin some of treatments being used
- Note: *Ixodes pacificus*, western blacklegged ticks, have been found infected with Bartonella
 - J Clin Microbiol. 2001 Apr;39(4):1221-6. Molecular evidence of Bartonella spp. in questing adult *Ixodes pacificus* ticks in California. Chang CC1, Chomel BB, Kasten RW, Romano V, Tietze N.

¹Ticks known to carry *Bartonella henselae* but transmission still being investigated by researchers. A 2004 PCR analysis of *I. Scapularis* ticks in New Jersey discovered that a higher percentage of ticks were infected with *B. henselae* than any of these other pathogens. In addition, *B. henselae* has been detected in the spinal fluid of patients co-infected with *Borrelia burgdorferi*, the agent of Lyme disease. (Columbia Lyme & TBD Research Center)

² J Clin Microbiol. 2004 Jun;42(6):2799-801. Prevalence of *Borrelia burgdorferi*, *Bartonella spp.*, *Babesia microti*, and *Anaplasma phagocytophila* in *Ixodes scapularis* ticks collected in Northern New Jersey. Adelson ME, Rao RV, et al. Medical Diagnostic Laboratories L.L.C., 133 Gaither Dr., Suite C, Mt. Laurel, NJ 08054, USA.



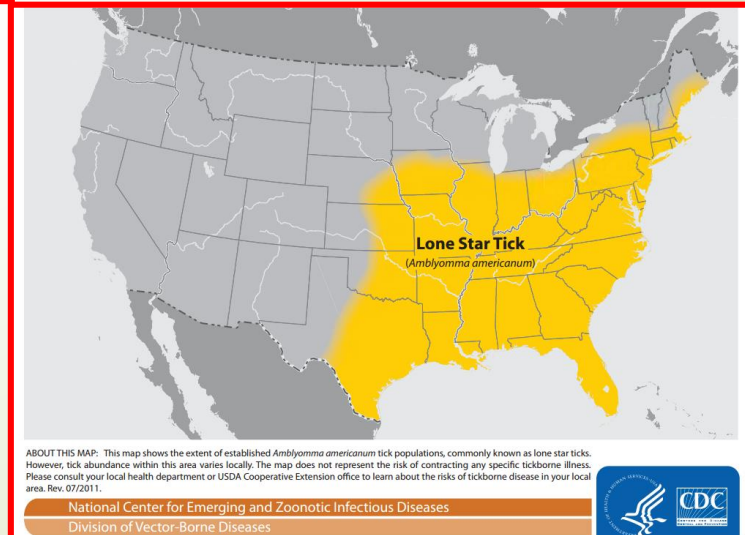
Lone star tick *Amblyomma americanum*

Transmits

- Alpha-gal meat allergy
- STARI (aka Master's Disease)
- Tularemia
- Heartland virus
- Tick paralysis (remove tick is cure)
- Q fever
- Ehrlichiosis
- Bourbon virus
- Rocky Mountain spotted fever*



*Lone star can carry the organism, still discussion if lone star can transmit RMSF- one case report

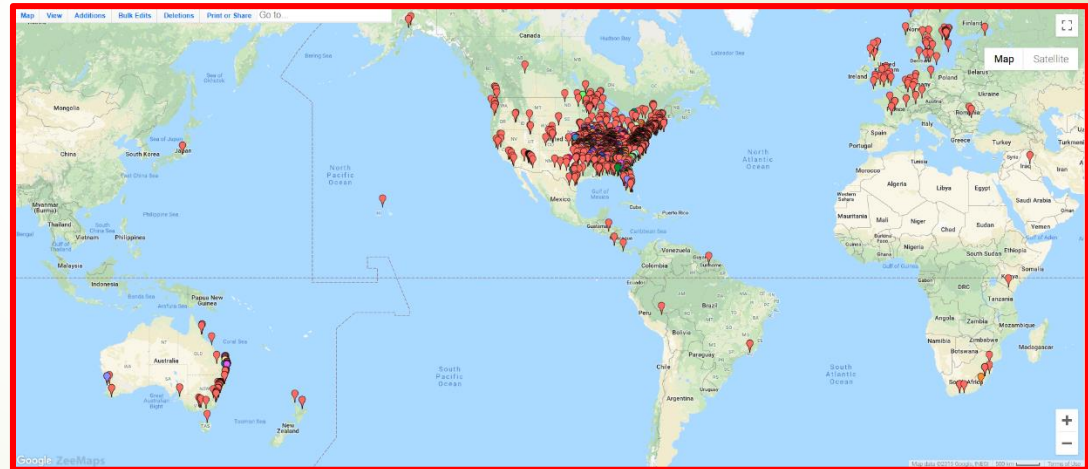
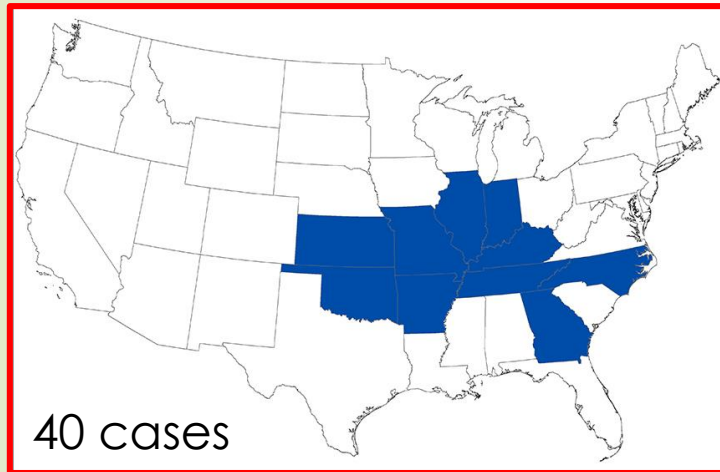


Lone star tick *Amblyomma americanum*



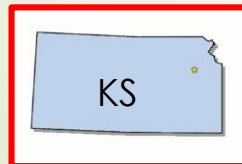
Heartland virus no test, no tx

Alpha gal allergy (lone star in US)



Used with permission from ZeeMaps Screenshot April 23, 2019

Bourbon virus ~6 cases no test, no tx

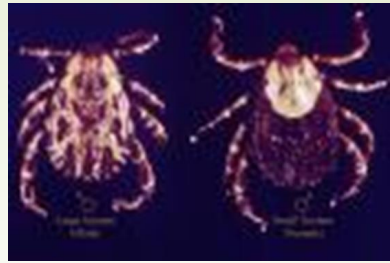


STARI (Southern Tick-Associated Rash Illness)

- From bite of Lone Star tick
 - Southern Tick-Associated Rash Illness
 - Also know as Master's Disease
- Infectious cause unknown
 - Formerly thought *Borrelia lonestari* cause
- Looks and acts like Lyme
 - EM-like rash, fatigue, headache, fever, muscle pain
- No test for it
- Same treatment as Lyme



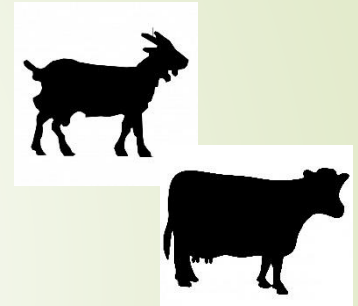
Q Fever



Bite of Rocky Mt. wood or lone star tick

□ Q fever

- Transmitted by lone star & Rocky Mt. wood ticks
- Caused by *Coxiella burnetii* bacteria
 - Also from inhaling Cb-containing dust
 - cattle sheep goat reservoirs
- Symptoms
 - High fevers up to 105°, severe headache, malaise, myalgia, chills and/or sweats, cough, nausea, vomiting, diarrhea, abdominal pain, chest pain
 - May include endocarditis, encephalitis, pneumonia, hepatitis, splenomegaly
- Tests
 - IFA titers
- Treatment- 2002-2014 50% of cases required hospitalization
 - Doxycycline
- Case Numbers ~ 175 in 2014 (been on rise)



American dog tick *Dermacentor variabilis*



Transmits

- Rocky Mountain spotted fever
- Tularemia
- Tick paralysis

**LDA Note:
Tick is in CO**



ABOUT THIS MAP: This map is not meant to represent risks for a specific tick-borne disease, because disease transmission is influenced by multiple factors beyond mere tick presence. This map has been designed to answer the question "What ticks should I be concerned about at a regional scale?" Please consult a local public health authority or USDA Agricultural Extension Office to determine more specific information at the state, county, or municipal level. Background data for this map is from the US National Atlas.



Rocky Mountain Spotted Fever

□ Rocky Mountain spotted fever

- Transmitted by American dog, wood, brown dog ticks
 - Unsettled whether lone star can transmit
 - “Rickettsia rickettsii Transmission by a Lone Star Tick, North Carolina”
 - Emerg Infect Dis. 2011 May; 17(5): 873–875. doi: 10.3201/eid1705.101530 PMID: PMC3321779 PMID: 21529399 Edward B. Breitschwerdt, corresponding author Barbara C. Hegarty, Ricardo G. Maggi, Paul M. Lantos, Denise M. Aslett, and Julie M. Bradley
- Caused by *Rickettsia rickettsii* bacteria
- Symptoms include
 - fever
 - headache
 - myalgia (tenderness/pain in muscles)
 - characteristic rash on wrists, ankles, soles, palms
 - Rash may be absent in early disease
- Treatment is doxycycline
- CDC: 5-10% mortality in clinical reviews¹
 - Dantas-Torres in Lancet 2007 20%



□ Increased new SW cases from brown dog tick

American dog tick *Dermacentor variabilis*

(L)Adult F & M

F laying eggs

(4,000-6000 eggs are laid)



Larvae, (R), sometimes hatch
infected with RMSF



Photo thanks; James Occi, MS, MA Rutgers, LDA Advisory Board

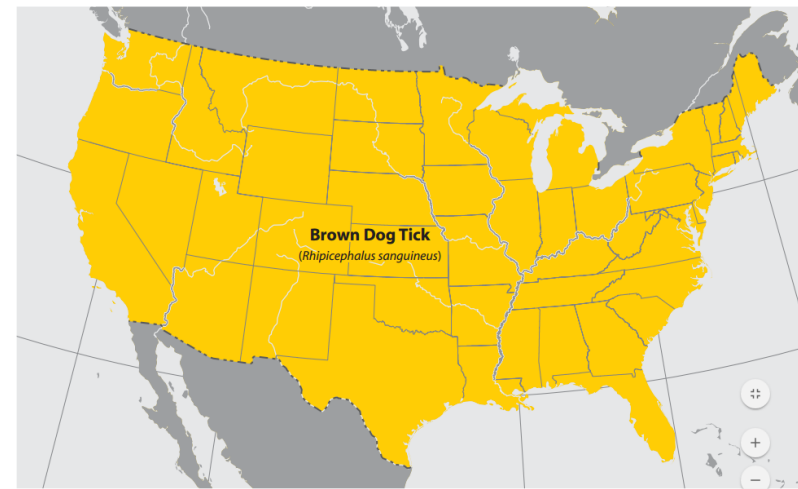
Brown dog tick *Rhipicephalus sanguineus*



Transmits

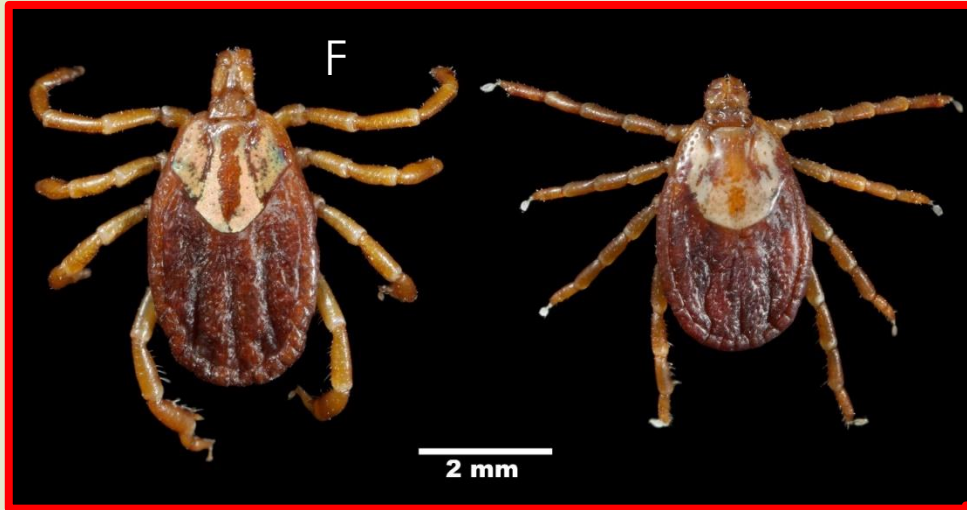
- Rocky Mountain Spotted Fever
- Mainly bites dogs
- Can bite humans
- Infests homes, dog kennels
- Can live entire life in house

Now transmitting RMSF
to humans in SW



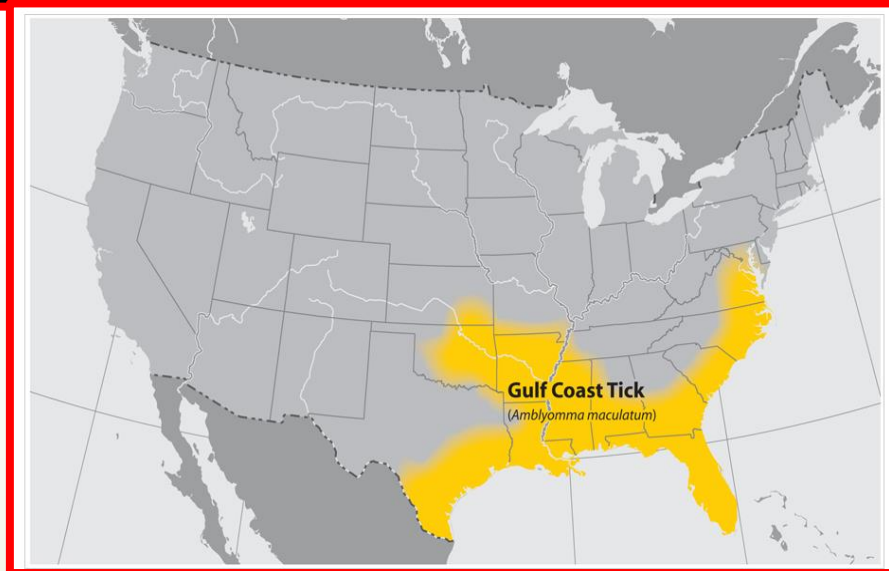
ABOUT THIS MAP: This map is not meant to represent risks for a specific tick-borne disease, because disease transmission is influenced by multiple factors beyond mere tick presence. This map has been designed to answer the question "What ticks should I be concerned about at

Gulf Coast tick *Amblyomma maculatum*



Transmits

- *Rickettsia parkeri* rickettsiosis



Rocky Mountain wood tick *Dermacentor andersoni*



Photo by CDC: Rocky Mountain Wood Tick

Transmits

- Rocky Mt. spotted fever
- Colorado tick fever
- Tick paralysis
- Q fever
- Tularemia

Rocky Mountain wood tick (*Dermacentor andersoni*)



Where found: Rocky Mountain states and southwestern Canada from elevations of 4,000 to 10,500 feet.

Transmits: [Rocky Mountain spotted fever](#), [Colorado tick fever](#), and [tularemia](#)

Comments: Adult ticks feed primarily on large mammals. Larvae and nymphs feed on small rodents. Adult ticks are primarily associated with pathogen transmission to humans.



Dermacentor occidentalis

Pacific Coast tick

Transmits

- Rickettsia 364 D
(*Rickettsia phillipii*)

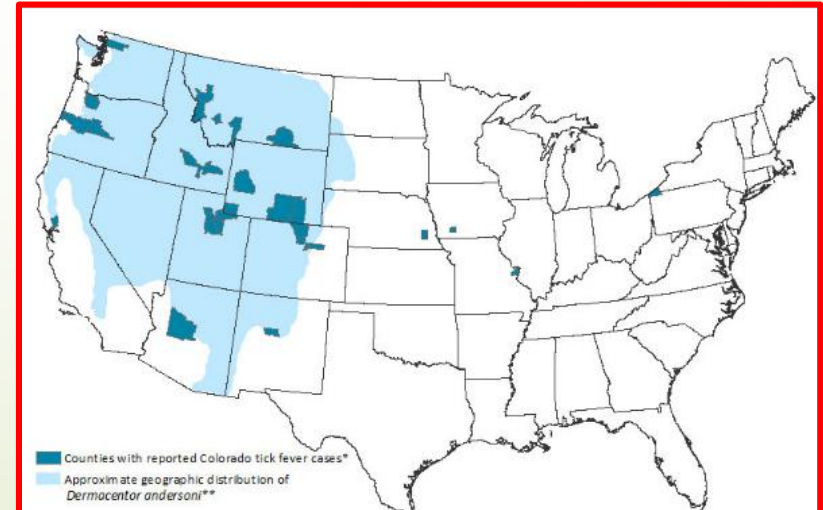


Dermacentor andersoni

Rocky Mt. wood tick

Transmits

- Colorado tick fever



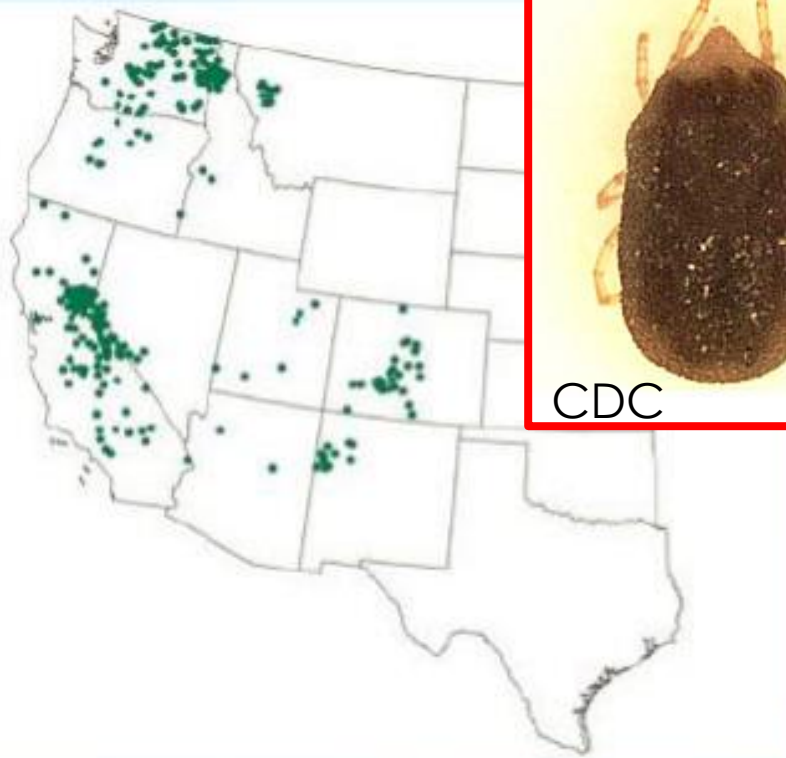
Tick-Borne Relapsing Fever 1990-2011

Transmitted by *Ornithodoros* ticks

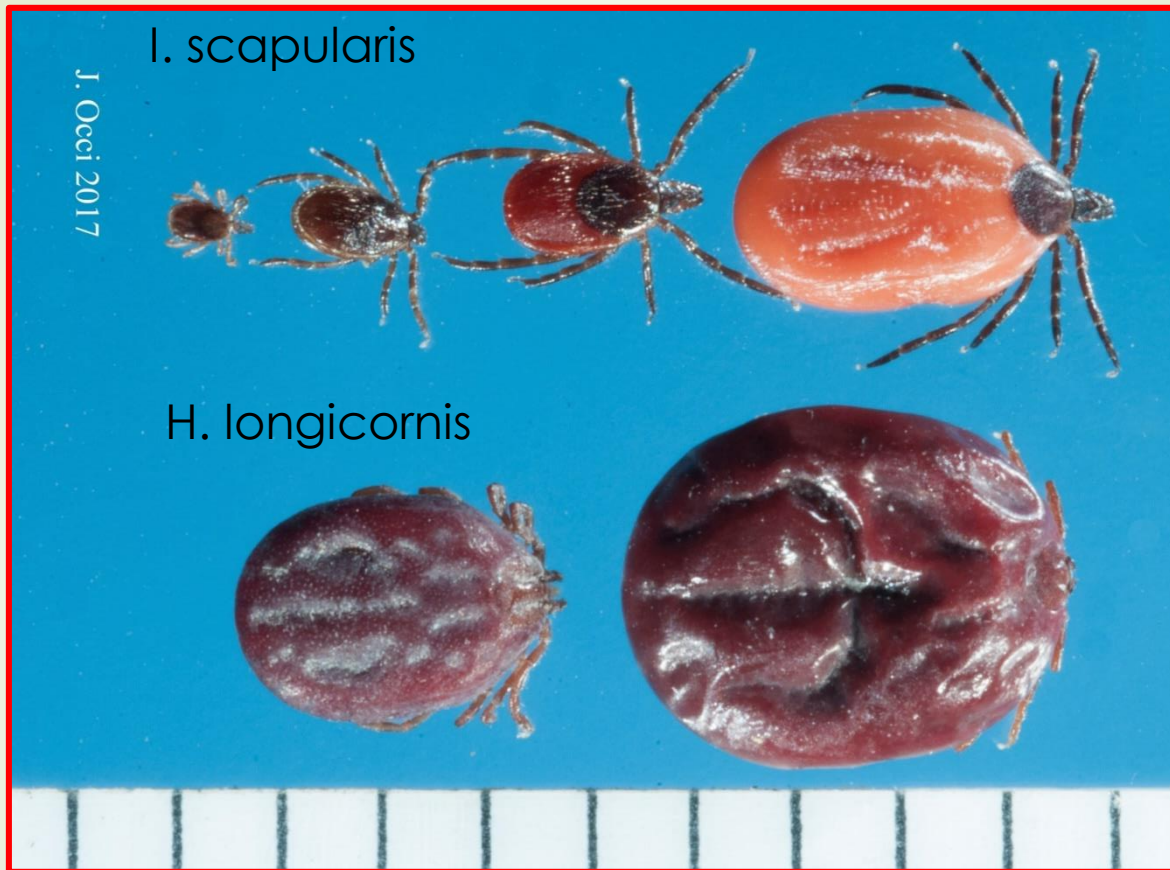
Left (green) each dot in county of exposure

Right (blue) each dot in county of residence

Cases of Tick-borne Relapsing Fever - United States, 1990 - 2011



Deer ticks & Longhorned ticks



2 female longicornis L- probably partially fed R- probably fully fed

- In China, found *B. miyamoto* *B. burgdorferi* sensu lato & unclassified *Borrelia* spp
- In other parts of Asia, SFTSV, bovine theileriosis & babesiosis in animals
- In 10 US states now: NJ, VA, WV, AR, NC, NY, PA, CT, NH, KY

Photo thanks James Occi, PhD (in progress) Rutgers/LDA Advisory Board



MyLymeData by LymeDisease.org

- Over 12,000 patients enrolled in patient registry
- How long until patients were diagnosed
 - 16% <4 months
 - 12% 5-11 months,
 - 17% 1-2 years,
 - 20% 2-6 years
 - 36% 6 years
- Summary
 - 36% unable to be diagnosed before at least 6 years
 - 84% not diagnosed within first 4 month
- 72% saw 4 or more docs before diagnosis
 - Leads to chronic illness
- 72% are misdiagnosed as
 - Psychiatric, FM, CFS, Thyroid, RA, MS, Lupus, Learning disabilities, Parkinson's, ALS, Etc.



Lyme Disease Controversy

❑ Controversy is over

- Chronic Lyme disease (CLD) aka
 - Persistent Lyme (PL)
 - Post Lyme syndrome (PLS)
 - Post Lyme disease syndrome (PLDS)
 - Post treatment Lyme (PTL)
 - Post treatment Lyme disease (PTLD)
 - Post treatment Lyme syndrome (PTLS)
 - Post treatment Lyme disease syndrome (PTLDS)
 - Ad infinitum
- CLD a term generally used by
 - treating physicians who are Lyme literate (LLMD)
 - patients with Lyme
 - advocates
 - some researchers (sometimes use persistent Lyme, Post treatment Lyme)
- “Syndrome” language promoted by those who believe chronic Lyme is NOT persistent infection; others often use it to ensure their work is not summarily dismissed
- **Estimation of cumulative number of post-treatment Lyme disease cases in the US, 2016 and 2020 Allison DeLong et al 4-24-19 BMC Public Health**
 - “Using statistical simulation techniques, we have estimated that the cumulative prevalence of PTLD in the US is high and substantially greater than the yearly incidence. We found that prevalence in 2020 is projected to be higher than 2016, and may be as high as 1,944,189 (CI: 1,619,988 to 2,304,147) cases. These findings are relevant to consideration of expected costs for Lyme disease treatment and the care of those with PTLD.”



Cases of PTLD (Post treatment Lyme Disease)

- ❑ Recent studies have shown that treatment failure rates may range from 10 to 20%
 - LDA note: Some studies indicate that more Lyme patients fail treatment than the 10-20%
 - LDA note: PTLD aka chronic Lyme
- ❑ A 2019 study by a statistician at Brown, Allison DeLong
 - PTLD prevalence estimates for 2016* ranged from 69,011 persons to 1,523,869 and
 - prevalence in 2020 is predicted to be higher than 2016, and may be as high as 1,944,189 cases
 - LD and its sequelae are responsible for significant numbers of school and work absences, and are estimated to cost more than \$1 billion per year for healthcare in the US

• Total number of PTLD cases at Index date 2016 is sum of surviving cases since 1981, or the 36 year prevalence. Total at 2020 in the 40 year prevalence

DeLong A et al "Estimation of cumulative number of post-treatment Lyme disease cases in the US, 2016 and 2020," *BMC Public Health*, 2019



Chronic Lyme Supported by Science

❑ Persisters

- Research on persisters/new antibiotics to eradicate persisters, new antibiotic protocols including pulsing
 - 2 researchers Y. Zhang, Johns Hopkins & K. Lewis, Northeastern separately investigating persisters & antibiotics
- What are persisters
 - Bacterial cells can escape effects of antibiotics without genetic change (T. Wood PSU)
 - These cells go dormant when treated with antibiotics, yet can grow again after treatment stops.
 - Unlike resistant cells which grow in presence of antibiotics, persisters don't grow in presence of antibiotics (T. Wood)

❑ Biofilms

- Research by E. Sapi University of New Haven
 - *European Journal of Microbiology and Immunology* 6 (2016)
 - Biofilms are colonies of bacteria encased in slime that act as one are highly resistant to antibiotics and host defense

❑ Animal studies

- “With the advent of increasingly sensitive PCR analyses, we and others have repeatedly demonstrated in dogs, mice and rhesus macaques that noncultivable spirochetes persist following antibiotic treatment.”
 - Stephen Barthold, DVM, PHD Testimony House Foreign Affairs Health Subcommittee 2012
- Barthold (mouse): antibiotic treatment is unable to clear persisting spirochetes, which remain viable and infectious, but are slowly dividing. (doxy, ceftriaxone, tigecycline)
- Phillip, Embers : (monkeys) non cultivable spirochetes persist following antibiotic treatment
- Straubinger: (dog) despite treatment of infected dogs for 1 mo. with ceftriaxone, doxycycline, or azithromycin, BbDNA continued to be detected as late as 12 mo. after therapy, tissues were consistently culture-negative.

❑ Xenodiagnosis in humans (A. Marquez, NIH 2014)

- Laboratory-reared larval *I. scapularis* ticks were placed on 36 subjects and allowed to feed to repletion. Ticks were tested for *B. burgdorferi*
- Xenodiagnosis was positive for *B. burgdorferi* DNA in a patient with erythema migrans early during therapy and in a patient with PTLDS. There is insufficient evidence, however, to conclude that viable spirochetes were present in either patient.
 - Marquez Clinical Infectious Disease 2014



Misusing CDC Surveillance Criteria

□ CDC statement (in gold) Reality (in black)

- Surveillance case definitions establish uniform criteria for disease reporting and should not be used:

1. as the sole criteria for establishing clinical diagnoses

Doctors are inappropriately requiring CDC surveillance criteria to diagnose.

2. to determine the standard of care for a particular patient

Doctors are using it to determine the standard of care.

3. to set guidelines for quality assurance, or to provide standards for reimbursement. ¹

Guidelines are being set and insurance companies are using criteria for reimbursement.

¹ <https://www.cdc.gov/lyme/healthcare/index.html>



Problems using CDC Surveillance criteria for Lyme Diagnosis

- ❑ Only 9% develop “classic bull’s” eye rash for Lyme¹
 - Bullseye is subset of EM rash which 60-80% of patients develop² (that figure includes bull’s eye) [LDA NOTE: Many postulate 50% or less get a Lyme rash]
 - 20-40% may not get a rash
- ❑ Current two tier testing
 - CDC’s two-tier testing system is very specific for Lyme disease (99%), gives few false +
 - Almost all tests have a uniformly low sensitivity (56%)--missing 88 of every 200 patients with Lyme disease. ³
 - By comparison, AIDS tests have a sensitivity of 99.5%--missing only one of every 200 infected patients. ³ Sensitive AIDS tests were developed less than 10 years into the disease, while archaic Lyme tests remain unreliable decades later
 - Commercial serological tests are based on one strain- One lab has developed a test based on 2 strains and reports high sensitivity in all phases of the diseases⁴
 - Antibodies complex with antigen, must dissociate antibody from target antigen ⁵
 - If NY had followed the 2-tier testing requirement for a particular year— a + ELISA followed by Western Blot, 81% of non-EM cases wouldn’t have been confirmed.⁶

¹ Stonehouse A1, Studdiford JS, Henry CA. An update on the diagnosis and treatment of early Lyme disease: "focusing on the bull's eye, you may miss the mark". J Emerg Med. 2010 Nov;39(5):e147-51. Epub 2007 Oct 18.

² <https://wwwn.cdc.gov/nndss/conditions/lyme-disease/case-definition/2017/>

³ Stricker RB, Johnson L. Lyme wars: let's tackle the testing. BMJ 2007; 335:1008

⁴ <http://www.igenex.com/innovations3.pdf>

⁵ Lancet 1990, Journal of Clinical Investigation 1994 & S. Schutzer et al, **JAMA** Vol 282, No. 20 *Borrelia Burgdorferi: Specific Immune Complexes in Acute Lyme Disease*, Nov. 24, 1999

⁶ According to a letter from the NY DOH to the CDC

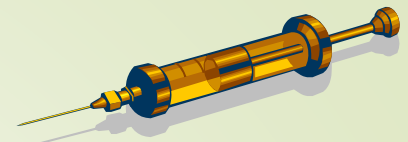


ILADS & IDSA Lyme Treatment Guidelines

- ❑ ILADS (International Lyme & Associated Diseases Society) Were last posted Lyme treatment guidelines on National Guidelines Clearing House under HHS– now defunct for lack of funding
 - August 2014 edition of the journal [Expert Review of Anti-infective Therapy](#)
 - Instead of a fixed duration for therapy, the Guidelines encourage clinicians to base therapy on the patient's response to treatment, including follow-up and therapy adjustments and take patient values into consideration
- ❑ IDSA (infectious Diseases Society of America)
 - IDSA Guidelines were removed from National Guidelines Clearing House-state
 - Existent ones are going to be redone
 - Asked for public input into process
 - LDA-LDo submitted input with group signon letter
 - Recently replied on website to public comments adding some people to panel ¹
 - “The panel includes three patients with confirmed Lyme disease and a parent of a pediatric patient with confirmed Lyme disease.”
 - “Project personnel changes:
 - A team at Tufts Medical will now develop the systematic review of this topic, as the medical librarians that had been working on the project were unable to sustain the volume of work related to the guideline
 - Due to personal and professional reasons unrelated to the nature of this specific guideline, panel member Dr. Charles Ericsson has resigned from the panel and will not be replaced
 - As a matter of course, Dr. Cameron Wolfe (IDSA Standards and Practice Guidelines Committee (SPGC) liaison to the Panel) rotated off the SPGC and has been replaced by new SPGC member Dr. Jeffrey Parsonnet.”
 - What happens next?
 - After a draft guideline is developed, it will be posted on the IDSA website for a 45-day public comment period. Additional information on the timing and availability of this draft will be posted to the IDSA website
 - **IDSA guidelines will not be published until 2020**



Story of Lyme Disease Vaccines



- ❑ No vaccine currently on market for humans
- ❑ GSK LymeRix withdrawn from market
 - Manufacturer cited lack of sales
 - Was a patient class action against vaccine
 - Complaints of arthritic & neurologic problems in people
- ❑ Baxter Vaccine: European trials (Phase 3) 2013 announced successful trial
 - Then sold off vaccine production
- ❑ Vaccine trial FDA Phase 1 Valneva French biotech Vaccine Dec 2016
 - Based on same core concept as now-defunct already FDA-approved LymeRix vac
 - Worked by injecting people with OspA, outer surface protein, of *Borrelia*
 - Taught body's immune system to recognize bacteria & launch an attack if showed up after a bite
 - Protein in US *Borrelia* not same as in European species of bacteria, or even from one region to another
 - Six (6) different types. LYMERix didn't address that.
 - Valneva-funded researchers based vaccine on all different kinds of OspA to cover US & European strains of *Borrelia*
 - July 2017 Valneva received FDA Fast Track Designation for VLA15
 - April 4, 2018 presented Phase 1 interim results of vaccine at World Vaccine Congress in DC
 - Dec. 2018 Valneva announced initiation of Phase 2 Clinical Development
 - Determine optimal dosage level & schedule for use in Phase 3 field efficacy studies, based on immunogenicity & safety data

HHS Vector-Borne Disease Working Group

- ❑ Presented first report to Congress October 2018
- ❑ WG Members of first panel 7 federal, 7 public (new ones TBA soon)
 - John N. Aucott, MD (Chair)
 - Kristen Honey, PhD, PMP (Vice-Chair)
 - Wendy Adams, MBA
 - C. Benjamin (Ben) Beard, MS, PhD
 - Captain Scott J. Cooper, MMSc, PA-C
 - Dennis M. Dixon, PhD
 - Richard I. Horowitz, MD
 - Captain Estella Z. Jones, DVM
 - Lise E. Nigrovic, MD, MPH
 - Allen L. Richards, PhD
 - Robert Sabatino
 - Vanila M. Singh M.D., MACM
 - Patricia V. Smith
 - Robert P. Smith, MD, MPH, FACP, FIDSA



Rec. 8.1 – NIH: Create an NIH tick-borne disease strategic plan, with public input during creation and implementation, to address tick-borne diseases, including all stages of Lyme disease. Include in the strategic plan the coordination of research funding across NIAID, NINDS, NIAMS, and NIMH to increase knowledge of pathogenesis, improve diagnosis, and develop and test new therapeutics for tick-borne diseases. Update every five years.

NIH requested input into strategic plan development

LDA submitted 6 page letter with recommendation to the NIH on 3-13-19. Can be found on LDA website.



HHS Report to Congress 2018

Diagnosis & Treatment

- ❑ Rec 5.1: Evaluate new technology or approaches for the diagnosis of Lyme disease and other tick-borne diseases.
- ❑ Rec 5.2: Include special populations, especially children, in Lyme disease and other tick-borne diseases diagnostic studies.
- ❑ Rec 6.1: Prioritize research into the potential pathogenic mechanisms (such as immune response, cross-reactivity, autoimmunity, bacterial persistence, coinfections, and other mechanisms) of persistent symptoms in patients who have received standard treatment regimens for tick-borne diseases, including Lyme disease.
- ❑ Rec 6.2: Promote research on animal models of *Borrelia burgdorferi* infection (that is, Lyme disease) and the mechanisms of disease processes in humans with an emphasis on pathologies that are currently lacking, for example, neuroborreliosis.
- ❑ Rec 6.3: Improve the education and research on transmission (including transmission via the blood supply and pregnancy) and treatment of other tick-borne diseases and coinfections.
- ❑ Rec 6.4: Conduct additional clinical trials appropriate to the target populations where gaps may exist.
- ❑ Recommendation 6.5: Improve the education and research on the pathogenesis of alpha-gal allergy, also known as the tick-caused “meat allergy.”



HHS Report to Congress 2018

Access to Care, Patient Outcomes

- ❑ Rec 7.1: Create a Federal repository for information on Lyme disease and other tick-borne diseases.
- ❑ Rec 7.2: Allocate increased funding for tick-borne disease in the areas of research, treatment, and prevention proportional to the burden of illness and need.
- ❑ Recs: Ensure the rights of those dealing with Lyme disease and tick-borne diseases & conditions by reducing the burden of the processes under which patients are currently diagnosed and treated & by which they access care. Basic protections must include, but not necessarily be limited to, those that
- ❑ Rec 7.3: Protect patients from employment discrimination.
- ❑ Rec 7.4: Protect students of all ages from discrimination. Recommendation
- ❑ Rec 7.5: Protect patients from health care and disability insurance coverage and reimbursement policies that are unduly burdensome.
- ❑ Rec 7.6: Protect the rights of licensed and qualified clinicians to use individual clinical judgment, as well as recognized guidelines, to diagnose and treat patients in accordance with the needs and goals of each individual patient.
- ❑ Major Issue 7.7: Testing and Diagnostic Bands: How They Are Used Today and What That Is Doing to Patients • Empower patients with data • Engage diverse stakeholders • Relay information as a neutral knowledge broker



Why We Need The Help of Congress

- ❑ 42,743 CDC reported newly diagnosed Lyme cases in 2017
- ❑ x10 to address underreporting = 427,430 new cases that occurred 2017
- ❑ 10-20% or more individuals will develop chronic symptoms
 - NIH not doing research in the chronic Lyme area
 - Government paying for chronic disease
- ❑ People cannot get diagnosed or treated
 - Doctors afraid to diagnose & treat and are unknowledgeable
 - Outdated tests less than 50% accurate,
 - Doctors must use same tests mandated in 1994
 - CDC Lyme surveillance criteria being used to diagnose
 - Little to no tick surveillance, people being told no Lyme in “our” state, no ticks
 - Human surveillance is broken, not uniform, NY for example has 27 counties which cannot be included in CDC surveillance numbers due to averaging, other states beginning to do similar things
- ❑ Spread of ticks transmitting 20 different tick-borne diseases/conditions
- ❑ Some of those TBDs have no testing or no treatment
- ❑ Little research funded for tick control
- ❑ There is no coherent federal strategy and SCANT MONEY from government
 - 2019: CDC \$12M NIH \$31M CDMRP under DoD \$5M = \$48M



National Lyme & Tick-Borne Diseases Control & Accountability Act of 2019

☐ HR 220

- Congressman Christopher Smith (NJ) Sponsor introduced 1-3-19
- Lead Co-Sponsor Colin Peterson (MN)

☐ Oversee creation of integrated national strategy for Lyme/TBDs

☐ Oversee/coordinate Lyme/TBD programs across HHS agencies/offices

☐ Goals

- Expanded research: epidemiological, basic, translational, clinical biological & biomedical research
- Surveillance improvement, reporting of Lyme & TBD & coinfections
- Develop effective diagnostic tests including direct detection
- Treatments to cure or improve lives of those with Lyme & TBD
- Design/support clinical trials
- Develop/maintain patient registries & ensure data confidentiality
- Document experiences of health care professionals
- Include individuals with chronic Lyme in efforts
- Coordinate with international bodies to integrate & inform fight against Lyme/TBD



House Lyme Disease Caucus

- ❑ **Christopher Smith (NJ-4) Co-Chair**
- ❑ **Collin C. Peterson (MN-7) Co-Chair**
- ❑ Steve Cohen (TN-9)
- ❑ Chris Collins (NY-27)
- ❑ Gerald E. Connolly (VA-11)
- ❑ Joe Courtney (CT-2)
- ❑ Antonio Delgado (NY-19)
- ❑ Vicky Hartzler (MO-4)
- ❑ Eleanor Holmes Norton (DC)
- ❑ James R. Langevin (RI-02)
- ❑ Sean Patrick Maloney (NY-18)
- ❑ Chellie Pingree (ME-1)
- ❑ Mark Pocan (WI-2)
- ❑ Bill Posey (FL-8)
- ❑ Ellen Stefanik (NY 21)
- ❑ Glenn Thompson (PA-5)
- ❑ Paul Tonko (NY-20)
- ❑ Jennifer Wexton (VA-10)



Let's Get Our Congressmen on Board!



Getting Rid of Ticks

- ❑ My favorite tick picture
 - Entomopathogenic fungus for tick control
 - *Metarhizium anisopliae* Strain 52



M. anisopliae on female *I. scapularis*
(Photo used with permission from Kirby Stafford, CT Agricultural Experiment Station)

Met52 (Novozymes Biologicals Inc.).

LDA does not make product recommendations or warranties. Read all manufacturer's instructions.



Thanks & Questions

□ Thanks:

- Congressman Christopher H. Smith (NJ-4)
- His office staff
- All the speakers
- All who helped organize the program
- Wall Township for the facility
- Audience for your attention

