LYME & OTHER TICK-BORNE DISEASES:
OVERVIEW OF TICKS & TBD IN US & PENNSYLVANIA

Webinar for Souderton Area High School, Pennsylvania

May 16, 2023/ 1:15pm

Presented by

Pat Smith, President
Lyme Disease Association Inc.

39-year Lyme Advocate & Educator
About Lyme Disease Association, Inc.

- Volunteer run, 32 yr. of service
- 95+% to programs
- Awarded 123 research grant
- 60 journal publications
- Awarded 159 educational grants to organizations; 117 grants for CME conf. scholarships
- Established LymeAid 4 Kids* medical help: $419,000+ awarded to date
- Presented 21 CME Lyme/TBD conferences for physicians/researchers, partnered with Columbia U.
- Guidestar member –earned highest level, platinum, for transparency
- Combined Federal Campaign (CFC) 2022, 17th year –federal workplace giving
- Partners with 40+ US Lyme organizations; under LDAnet umbrella
- Partner w/ Environmental Protection Agency PESP Program-Pesticide Environmental Stewardship
- LDA President testified before 2 different US House Committees on Lyme Disease in DC
- Invited to CDC Vector-Borne Diseases Branch, Ft. Collins, twice & to CDC Atlanta Lyme in South workshop-co-chaired section
- Website free doctor referral, brochure ordering online for S&H only
- You Tube Channel, Facebook, social media

www.LymeDiseaseAssociation.org
https://www.facebook.com/LymeDiseaseAssociation
• Lyme Disease Association, Time for Lyme, Columbia Partner: 1st endowed research center in world for Lyme/TBD
• Mission includes studies of new diagnostic tests, clinical phenomenology, immunopathogenesis, co-infections, genetic markers of vulnerability, brain imaging, neuroropathology of post-mortem brains, well-controlled studies of new treatments and tick pathogens
• Many peer-reviewed studies from this Center
Lyme Disease Spread: Worldwide
Found in more than 80 countries
### 2019 LDA State Ranking by Reported CDC Lyme Cases

<table>
<thead>
<tr>
<th>State Ranking</th>
<th>Reported Cases</th>
<th>Actual Cases (10x = actual cases)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pennsylvania</td>
<td>8998</td>
</tr>
<tr>
<td>2</td>
<td>New York</td>
<td>4243</td>
</tr>
<tr>
<td>3</td>
<td>New Jersey</td>
<td>3619</td>
</tr>
<tr>
<td>4</td>
<td>Wisconsin</td>
<td>2178</td>
</tr>
<tr>
<td>5</td>
<td>Maine</td>
<td>2167</td>
</tr>
<tr>
<td>6</td>
<td>New Hampshire</td>
<td>1710</td>
</tr>
<tr>
<td>7</td>
<td>Minnesota</td>
<td>1528</td>
</tr>
<tr>
<td>8</td>
<td>Maryland</td>
<td>1417</td>
</tr>
<tr>
<td>9</td>
<td>Connecticut</td>
<td>1233</td>
</tr>
<tr>
<td>10</td>
<td>Virginia</td>
<td>1199</td>
</tr>
</tbody>
</table>

CDC: ~476,000 cases diagnosed and treated annually in US according to Insurance claims.
CDC Reported Cases
1990-7,943
2019-34,945
1990-2019-716,302

“Recent estimates using other methods suggest that approximately 476,000 people may get Lyme disease each year in the United States”
https://www.cdc.gov/lyme/datasurveillance/index.html#:~:text=Each%20year%2C%20approximately%20476%2C000%20cases%2C%20the%20United%20States%20every%20year.
LYME DISEASE ASSOCIATION (LDA)

U.S. LYME DISEASE REPORTED CASES 1990–2019*

Click states to view history


* 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.

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).

Source: Data compiled from CDC pub data (MMWR/DVBD)  
©2021 Lyme Disease Association, Inc.  
www.LymeDiseaseAssociation.org
Lyme Disease Association, Inc.
Analysis of Lyme Disease Data by Age from 2001-2017

Source Data: CDC Lyme Disease Reported Case Numbers 2001-2017 by Age
Ages 0-19 at High Risk

Source figures accessed 9/15/19 from https://www.cdc.gov/lyme/stats/graphs.html
Total case numbers: 383,846
© 2019  Lyme Disease Association, Inc.
Born & Unborn Affected by Lyme in Humans

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

Photo free online: Camila Cordeiro
Fair Health Study Infographic

LYME DISEASE - A Continuing Concern

Private insurance claim lines with a Lyme disease diagnosis in the United States

From 2016 to 2021:
- In rural areas, increased 60%
- In urban areas, increased 19%

From 2007 to 2021:
- In rural areas, increased 357%
- In urban areas, increased 65%

In June and July, claim lines with Lyme disease diagnoses were more common in rural than urban areas. But from November to April, claim lines with Lyme disease diagnoses occurred more often in urban than rural areas.

Claim Lines with Lyme Disease Diagnoses: Rural-Urban Percentage by Month, 2016-2021

Source: Fair Health’s FH NPIC ® database of more than 36 billion privately billed healthcare claim records from more than 70 contributors nationwide. “Copyright 2022, FAIR Health, Inc. All rights reserved. Used with permission.”
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
  - Can get Ehrlichiosis & anaplasmosis

- IDEXX Ref. Labs database 6-13-15 thru 1-17-17 retrospective
  - Study in Bb & Ehrlichia areas, 846,626 canine chemistry/urinalysis
    - Dogs had 43% > risk of developing kidney disease when *Borrelia* antibodies were present;
    - Dogs had 300% > risk of developing kidney disease when Ehrlichia antibodies were present

- There is a Lyme vaccine for dogs- two sides to the story
  - M. Littman, R. Goldstein *Today’s Veterinary Practice, 1.1.14* “Vaccinating Dogs Against Lyme disease: Two Points of View”
    - “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*
  - 2,727 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

- Cat Ownership & Rural Residence Are Associated with Lyme Disease Prevalence in the Northeastern US

Canine TBD in Pennsylvania

- **Companion Animal Parasite Council (CAPC)**
  - Independent non-profit, professionals

- **CAPC 2022 Lyme Forecast**
  - “High risks of Lyme disease persist in all portions of the Northeast, the upper mid-western states of Wisconsin, Minnesota and the upper peninsula of Michigan. A higher-than-normal risk continues in North Dakota, northeastern South Dakota, Iowa, Illinois, and eastern Kentucky.” [https://capcvet.org/articles/2022-forecasts/](https://capcvet.org/articles/2022-forecasts/)

- **2022 TBD PA dog numbers for CAPC** [https://capcvet.org/maps/#/2022/all-year/lyme-disease/dog/united-states/pennsylvania](https://capcvet.org/maps/#/2022/all-year/lyme-disease/dog/united-states/pennsylvania)

  - **Lyme disease**
    - 2022 593,959 dogs tested
    - 8.91% + (1/11)
  - **Anaplasmosis**
    - 593,958 dogs tested
    - 7.25%+ (1/15)
  - **Ehrlichiosis**
    - 593,959 dogs tested
    - 1.19%+ (1/100)

- **CAPC concerning its website data**
  - Data provided by IDEXX Labs & ANTECH Diagnostics. CAPC estimates it represents <30% of activity in the geographic region
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 in 2 counties had Bb
  - 2.4 & 7.3% of unattached ticks in 2 counties had Bb
  - Mechanism in deer may clear Bb from attached

- Vectors: Ticks
  - Transmit disease

* NOTE: A LDA web search finds these animals (East) in Nebraska, Are they all hosts, do not know


Photo Thanks: Mouse, J. Occi, PhD, Rutgers; Western gray squirrel, John C. Avise, UCI; Deer, Pat Smith, LDA
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

- **NOTE:** Ticks can be active all year round. Peak activity in PA from spring-May & mid August-November

Photos: James Occi, PhD, LDA Professional Advisory Board

soft tick photo: Matt Pound USDA Agricultural Research Service, Wikimedia
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

Photo courtesy of the late Manfred Bayer, MD
Proper Tick Removal

Do not
- put anything on tick
- burn the tick
- touch the tick with fingers
- squeeze the tick body

Do use pointed tweezers*, close to skin on “head” of tick *(or special tick removal tool)
- pull straight out, do not twist or squeeze
  - can inject anything it has into you
  - greatly increases risk of infection

Do clean skin area with antiseptic afterwards

Do call your doctor

Do stick tick in tape for permanent disposal

Tick Attachment Time & Lyme Transmission

✓ Longer a tick attachment, greater the risk of infection
  • Why days of attachment used as necessary for transmission
    o Generally Lyme bacteria (Borrelia burgdorferi) in tick midgut
    o 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
    o “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 virus


Photo thanks: the late Ed Masters, MD, Missouri
Blacklegged/deer tick (Ixodes scapularis)

CDC
Deer Ticks & Poppy Seeds

Poppy seed-sized nymph deer ticks produce the most disease.

Photo Thanks: James L. Occi, PhD; LDA Professional Advisory Board
Deer Tick Laying Eggs (Ovipositing)

Photo Thanks: James L. Occi, PhD; LDA Professional Advisory Board
Deer Tick Stages
eggs, larvae, nymph, adult

Photo Thanks: James L. Occi, PhD; LDA Professional Advisory Board
Blacklegged (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)

*One strain of babesia, B. odocoilei, can be passed by transovarial transmission: female to eggs to larvae of blacklegged tick

**CDC hasn’t yet determined bartonella is tick-borne
American Dog Tick & Deer Ticks

Size difference on paper clip

Photo Thanks James Occi, PhD; LDA Professional Advisory Board
American dog tick (*Dermacentor variabilis*).

**Transmits**
- Rocky Mountain spotted fever
- Tularemia
- Tick paralysis

“Tick paralysis is thought to be caused by a toxin in the saliva of an attached tick. People with tick paralysis can experience weakness or paralysis that gradually moves up the body.

These symptoms can sometimes resemble other neurologic conditions (for example, Guillain-Barré syndrome or botulism). Patients typically regain movement within 24 hours of removing the tick.”

1 CDC [https://www.cdc.gov/ticks/symptoms.html#:~:text=Tick%20paralysis%20is%20thought%20to,%2DBarr%C3%A9%20syndrome%20or%20botulism).]
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
Brown dog tick (*Rhipicephalus sanguineus*)

Transmits

- Rocky Mountain Spotted Fever

**Tick**

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

Now transmitting RMSF to humans in SW

- Rocky Mountain spotted fever (RMSF), caused by *Rickettsia rickettsii*, is a tick–borne disease with epidemic potential that has been reported in U.S.–Mexico border areas.

- During 2010, 1,682 cases of RMSF were reported in the United States. Arizona reported 41 cases during this time period, all associated with tribal lands and transmission from *Rhipicephalus sanguineus*, the brown dog tick.

- The disease has also been reported along the Mexican side of the border. During 2009–2010, over 1,000 cases of RMSF were reported in Mexicali, Mexico, also linked to transmission by *Rhipicephalus sanguineus*, and spread through infected ticks by stray and free-roaming dogs. Subsequent surveillance efforts have suggested that sporadic RMSF cases, likely associated with the brown dog tick, are widespread throughout many Mexican border states.

Photo credit: Centers for Disease Control & Prevention
Lone star tick (*Amblyomma americanum*)

**Transmits**
- Alpha-gal meat allergy (causes)
- 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*): New TB Virals & TB Condition

Heartland virus testing@CDC, supportive tx 1

Heartland virus disease cases by state, as of January 2021

As of January 2021, Heartland virus disease cases have been identified in residents from the following states: Arkansas, Georgia, Illinois, Indiana, Iowa, Kansas, Kentucky, Missouri, North Carolina, Oklahoma, and Tennessee.

Kansas (KS), Missouri (MO), Oklahoma (OK)

A Lonestar in SE PA has tested + for Heartland

Bourbon virus ~ molecular/serologic testing @ CDC, supportive therapy only3

As of 2017, 50 cases reported in Midwestern & Southern states; Deaths reported

Alpha gal allergy (lone star in US) 2

Alpha gal map:Zee source screen shot 5.1.23

1 https://www.cdc.gov/heartland-virus/index.html

3 https://www.cdc.gov/bourbon-virus/index.html
Gulf Coast tick  (Amblyomma maculatum)

Transmits

- *Rickettsia parkeri* rickettsiosis

**Signs & Symptoms**
- Inoculation eschar
- Fever
- Headache
- Muscle aches
- Rash (sparse maculopapular or papulovesicular on trunk & extremities)

**Diagnosis**
- DNA by PCR is eschar swab, wh. bld., or skin biopsy
- IFA assay

**Gen. Lab Findings**
- Mild leukopenia/thrombocytopenia, mild > hepatic transaminase

Thanks to Graham Snodgrass, Army Public Health Center
Rocky Mountain wood tick  (*Dermacentor andersoni*)

Transmits
- Rocky Mt. spotted fever
- Colorado tick fever
- Tick paralysis
- Q fever
- Tularemia
**Far West & West Coast Ticks**

**Western blacklegged tick**
*Ixodes pacificus*

- Transmits:
  - Lyme disease
  - *Borrelia miyamotoi*
  - Anaplasmosis
  - Ehrlichiosis
  - Babesiosis
  - Rickettsiosis
  - Powassan

**Pacific Coast tick**
*Dermacentor occidentalis*

- Transmits:
  - Rocky Mt. spotted fever
  - Tularemia
  - Pacific Coast tick fever
    - (364 D rickettsiosis)
    - (aka: *Rickettsia phillipi*)
Unidentified ticks found on sheep at Hunterdon Co., NJ, Farm 11.21.17

Found large tick infestation in multiple life stages on property

Sheep with no travel history, tick infested, treated with permethrin
  - Waited to see if ticks died over winter—wintered over

Identified as *Haemaphysalis Longicornis*
  - Among 27 adults, 41 nymphs 1058 larvae collected, 1 male
  - Invasive populations like this are exclusively parthenogenetic
  - Can reproduce without male
  - 2022—Ticks now confirmed in 17 states
    - NJ, VA, WV, AR, NC, NY, PA, CT, NH, KY, MD, TN, DE, GA, MO, OH, RI, SC

---

1. *Entomology Today, NJ Ticks*

*Photo thanks: James Occi, PhD; LDA Advisory Board*
Longhorned Tick (*Haemaphysalis longicornis*) Kills Cows in US

- North Carolina 2019
  - 5 cows killed by *H. longicornis*
  - 1000+ ticks found on each cow
  - Cause of death acute anemia according to Dept. of Agriculture
    - Cows drained of blood from ticks
- “Longhorned” tick is already known to transmit several human diseases, including spotted fever rickettsiosis in native East Asian countries – China, Japan and Australia
- **Government has not reported any human disease cases in US to date**
- Does not require male to fertilize eggs
- Pathogen Update
  - Bourbon virus (BRBV) detected in *Haemaphysalis longicornus* in several VA counties ¹
  - One tick tested + in PA study for *Borrelia burgdorferi ss*²

² Price, Keith J. et al, Bb ss DNA in Field Collected *Haemaphysalis longicornus* Ticks, PA; EID, February 2021

Photo thanks: James Occi, PhD; LDA Advisory Board
3 Medically Important Ticks in Pennsylvania & Assoc. Diseases

- **American Dog Tick**
  - *Dermacentor variabilis*
  - Diseases in PA
    - Spotted Fever rickettsiosis

- **Lone Star Tick**
  - *Amblyomma americanum*
  - Diseases in PA
    - Ehrlichiosis, STARI, Tularemia, Alpha-gal allergy

- **Blacklegged Tick**
  - *Ixodes scapularis*
  - Diseases in PA
    - Lyme disease
    - Babesiosis
    - Ehrlichiosis
    - Anaplasmosis
    - Borrelia miyamotoi (diagnosis to be considered)

- A 117 yr. retrospective analysis of PA ticks in 2019 identified 24 species in PA

---

1. *Info from Pennsylvania Department of Health advisory (8.26.22)*
LDA provided grant to Pike County, PA 2018 (baseline studies)
- Tested deer ticks for *Borrelia burgdorferi*, Lyme bacteria, 39% by PCR, also for Bartonella sp, 18.5%
- Remainder tested less %
  - *Borrelia miyamotoi*
  - *Anaplasma phagocytophilum*
  - *Babesia microti*
  - *Mycoplasma sp*
  - *Powassan* Virus lineage II

LDA provided grant to Pike County, PA 2021
- Five tick-borne pathogens screened through real-time PCR, and the following results were found:
  - (adult%, nymph%)
    - *Borrelia burgdorferi* (45.99%, 18.94%)
    - *Anaplasma phagocytophilum* (12.29%, 7.95%)
    - *Babesia microti* (4.97%, 5.30%)
    - *Borrelia miyamotoi* (1.38%, 1.89%)
    - Powassan virus lineage II/deer tick virus (2.07%, 0.76%)

---

Lyme Disease That You Know (*borrelia burgdorferi*)

Overview slide #1

- Transmitted by
  - Black legged ticks ("deer ticks") *I. scapularis*
  - Western blacklegged ticks *I. pacificus*

- Caused by *Borrelia burgdorferi*

- Symptoms
  - Early: flu-like illness; muscle aches and pains; joint pain and/or swelling; fatigue; malaise, fever; headache
  - Possible rash: Bullseye (9%)
    - is subset of EM rash which 60-80% of patients develop
    - (that figure includes bull's eye)
  - Later symptoms-can attack all systems in the body

- Testing
  - various tests including two tier: Eliza, if - or equivocal, followed by WB

- Treatment: doxycycline


Photo credit: James L. Occi, PhD, LDA Professional Advisory Board
Lyme Rashes

- Not everybody gets one!
- Can look different than classic bull’s eye\(^1\)
- Can be on other places on your body than the bite site (disseminated disease)

\(^1\)Forrester 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.

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

Columbia University Rash Poster

Can download & print from LDA website


Borrelia burgdorferi
Courtesty Dave Dorward, PhD; NIH

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-hme.org
Poster creation supported by Grant from the Lyme Disease Association, Inc. http://www.LymeDiseaseAssociation.org
Lyme Signs & Symptoms #2

- **Musculoskeletal:** joint pain or swelling or stiffness, muscle pain; migrating muscle pain or cramps; shin splints; neck or back stiffness; joint pain and/or swelling; or cramps that may migrate, TMJ, neck creaks & cracks, tender soles

- **Reproductive:** testicular pain/pelvic pain; menstrual irregularity; unexplained milk production (lactation); sexual dysfunction or loss of libido

- **Cardiac/Pulmonary:** chest pain or rib soreness; shortness of breath; heart palpitations, pulse skips; heart block; heart murmur; valve prolapse

*Note: Cardiac poster can be downloaded for free from LDA website & printed [https://lymediseaseassociation.org/lyme-tbd/medical/cardiac-lyme/]*
Lyme Signs & Symptoms #3

- **Neurological**
  - muscle twitching; headache; tingling, numbness, burning or stabbing sensations; facial paralysis (looks like Bell’s palsy);
  - dizziness; poor balance; increased motion sickness; light-headedness; wooziness; difficulty walking; tremor; confusion;
  - difficulty thinking/concentrating/reading; forgetfulness, poor short term memory; disorientation (getting lost, going to wrong place);
  - difficulty with speech; double or blurry vision; eye pain; blindness; increased floaters; increased sensitivity to light or sound or smell; buzzing or ringing in ears; ear pain; decreased hearing or deafness; seizure activity; white matter lesions;
  - low blood pressure
Lyme Signs & Symptoms # 4

**Neuropsychiatric:**
- mood swings; irritability; depression; disturbed sleep (too much, too little, early awakening); personality changes; obsessive-compulsive disorder (OCD); violent outbursts; anorexia; paranoia; panic/anxiety attacks; hallucinations (visual, auditory, sensory)

**Gastrointestinal:**
- nausea or vomiting; loss of appetite; GERD; change in bowel function (constipation, diarrhea); gastritis; abnormal cramping; cystitis; irritable bladder or bowel dysfunction; newly diagnosed irritable bowel syndrome (IBS)

**Other:**
- fever, sweats, or chills; weight change (loss or gain); fatigue; tiredness; hair loss; swollen glands; sore throat; difficulty swallowing; swelling around the eyes & swelling feet
Lyme Disease You May Not know: *Borrelia mayonii*

- **Causes Lyme disease right now in Upper Midwest**
  - Not detected in ~25,000 blood samples from other parts of US
  - A strain similar to *Borrelia burgdorferi*, wi/ *Borrelia sl* complex
  - Lancet Infectious Diseases 2-18-16
  - MN DOH

- **Transmitted by**
  - Blacklegged ticks (“deer ticks”) (*mayonii* found in several British Columbia ticks)
  - Id’ed in at least 2 co. in WI from collected ticks; Pts. in MN & WI, ND in study

- **Symptoms**
  - Early symptoms -fever, headaches, rash, neck pain ; Later stages-arthritis
  - Difference from Bb symptoms may include
    - Nausea & vomiting
    - More diffuse rashes
    - Higher concentration of bacteria in blood: 180 fold higher than Bb
  - Dermatology Times 10-10-16

- **No difference in ability of larvae originating from MN & larvae from CT to acquire B. mayonii from infected mice & pass spirochetes to nymph (11.6%/13.3% respectively)**
  - Concluded: *Ixodes scapularis from Upper Midwest & Northeast did* not differ in efficiency as vectors for *B. mayonii* ¹

- **B. mayonii found in animals in Upper Midwest**
  - MN: white footed mouse, American red squirrel
  - WI: eastern chipmunks, high infection prevalence –species may be important reservoir in Upper Midwest²

- **Testing/treatment for Lyme (B. mayonii)**
  - Current Lyme testing (Bb)/Doxycycline

---


Co-Infections

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

Photo thanks to James L. Occi, PhD, LDA Advisory Board
Anaplasmosis & Ehrlichiosis

Anaplasmosis (HGA), formerly Ehrlichiosis (HGE) ¹

- *Anaplasma phagocytophilum* bacteria transmitted by *I. scapularis* & *I. pacificus*
- Symptoms
  - Onset of anaplasmosis generally begins within a week of a tick bite
  - Early signs: fever, severe headaches, malaise, muscle pains, chills, nausea, vomiting
  - If treatment delayed or other medical conditions present, can cause severe illness; age risk factor
  - Signs/symptoms severe (late stage): respiratory, bleeding, organ failure, death
- Tests: Blood smears, IFA IgG, maybe IgM (Ab frequently negative 1st weeks); and
  - PCR (1st wk. most sensitive, neg. does not rule out; don’t withhold tx based on negative)
- Treatment—Doxycycline
- In rare cases, spread by blood transfusion

Ehrlichiosis ²

- Caused by *Ehrlichia chafeensis* bacteria
  - Transmitted by the lone star tick
- Caused by *E. ewengii*
  - Transmitted by lone star tick
- Caused by *Ehrlichia muris eauclairensis*
  - Transmitted by deer tick (blacklegged)
- Tests: Blood smears, IFA IgG (freq. – 1st wk.), PCR (most sensitive 1st wks., less after abx)
- Symptoms & Treatment
  - Fever, chills, headache, muscle aches, and sometimes upset stomach
  - Doxycycline for all ages

*Ehrlichia* spread through blood transfusion & organ transplant in rare cases

Note: In 2013 anaplasmosis in double digits for PA 1st time. In 2021, 600+ cases ³ Dxed by Hershey ³

https://www.cdc.gov/anaplasmosis/index.html

https://www.cdc.gov/ehrlichiosis/index.html

³ Ingram D, Open forum Inf Dis, 4.12.23
Babesiosis

- One of most common co-infections w/ Lyme, parasite
- Can be transmitted through blood supply
- FDA finally approved test to screen for *Babesia microti* 3-6-18
  - *Microti*: main species US to cause infection, transmitted by deer tick
- FDA approved screen test for *Babesia microti*, *B. duncani*, *B. Divergans*, *B. venatorum* 2-07-19
- Rare cases congenital transmission
- Microscopic diagnosis, blood smear, IFA, PCR
- Can be fatal to elderly or those w/no spleen
- Lyme coinfection—can have more serious symptoms
- 14,042 reported cases 2011-2019 (CDC.gov)

**Symptoms**
Fever, chills, fatigue, headache, muscle pain, sweats, anemia

**Symptoms on routine lab work**
Hemolytic anemia, thrombocytopenia proteinurea, hemoglobinuria, elevated liver enzymes, BUN, creatinine

**Treatment**
atovaquone + azithromycin
clindamycin + quinine

https://www.cdc.gov/parasites/babesiosis/index.html
**Borrelia miyamotoi Disease**

- **Caused by:** Spirochete-shaped bacteria closely related to Borrelia relapsing fever group
  - more distantly related to *Borrelia burgdorferi* causing Lyme disease

- **Transmitted by:**
  - black legged ticks ("deer ticks") *I.scapularis*
  - western blacklegged ticks *I.pacificus*

- **Symptoms**
  - fever, may be recurring*; headaches, chills, body/joint pain, fatigue; arthralgia/myalgia
  - uncommon: dizziness, confusion, vertigo, dyspnea, nausea, abdominal pain, diarrhea, anorexia
  - *last ~3 days and are separated by afebrile periods of ~7 days duration.

- **Testing:** Microscopy; Serology may vary by lab; PCR testing
  - speciation usually determined by geography
  - western state, high elevation— *Borrelia hermsii*
  - southern state, low elevation— *Borrelia turicatae*

- **Treatment:** doxycycline; also zithro, ceftriaxone
  - susceptible to penicillin & other drugs

---

**PA Health Dept. Adv. 8.26.22** *Borrelia miyamotoi* disease has been detected in multiple Pennsylvania residents. Healthcare providers (HCPs) should consider it in patients presenting with compatible symptoms.

Powassan virus neuroinvasive disease cases reported by state of residence, 2012–2021

Source: ArboNET, Arboviral Diseases Branch, Centers for Disease Control and Prevention

Data table: From 2012 through 2021, Powassan virus neuroinvasive disease cases have been reported in Connecticut (13), Indiana (1), Maine (12), Massachusetts (43), Minnesota (31), New Hampshire (5), New Jersey (13), New York (23), North Carolina (1), North Dakota (2), Ohio (1), Pennsylvania (9), Rhode Island (5), and Wisconsin (30).
Powassan Virus

- Caused by bite of ticks primarily found in eastern half US
  - *Ixodes scapularis* (blacklegged or deer tick)
  - *Ixodes cookei* (groundhog tick) *rarely bite humans*
  - *Ixodes marxi* (squirrel tick) *rarely bite humans*
  - and rarely through blood transfusions

- Transmission time of virus can be as soon as 15 minutes after attachment

- Symptoms – incubation period 1–4 weeks after bite
  - Initial: Headache, fever, nausea, vomiting, generalized weakness
  - Can progress to: encephalitis, meningoencephalitis, or aseptic meningitis
    - Symptoms of encephalitis may include altered mental status, seizures, speech problems (aphasia, dysarthria), paresis or paralysis, movement disorders, and cranial nerve palsies
  - Encephalitis (brain infected) & meningitis (membranes around brain/spinal column)
    - Death (10% of Powassan neuroinvasive are fatal)
    - 50% of survivors have long lasting neurologic deficits (headaches, muscle weakness, focal paralysis, cognitive)

- Treatment
  - Supportive only available treatment; severe disease often hospitalized

- Testing: Serum/CFS virus specific IgM; ELISA; Immunoassays for POV IgM; viral RNA e.g. [RT-PCR]; IHC (immunohistochemistry)@CDC & some state labs or reference labs

- Nationally notifiable condition: All cases should be reported to local public health authorities in a timely manner. Reporting can assist local, state, and national authorities to implement control measures to reduce future infections.

- CDC Website 1/26/2023 Preliminary diagnosis is based on the patient’s clinical signs and symptoms, location where infection likely occurred (including places and dates of travel), and activities leading to risk of possible exposure to the virus primarily through *Ixodes* species ticks or rarely, blood transfusions.

1 [https://www.columbia-lyme.org/powassan-virus](https://www.columbia-lyme.org/powassan-virus)
2 [https://www.cdc.gov/powassan/index.htm](https://www.cdc.gov/powassan/index.htm)
Bartonellosis

- Bartonella sp. illness (bacteria)
  - Transmission
    - fleas, lice, sand flies, cat scratches & bites, cat saliva on broken skin or mucosal surfaces (nose, mouth, eyes)
    - Can be carried by *Ixodes scapularis* (blacklegged or deer tick) 1,3
  - 2004 study in NJ
    - PCR of *I* ticks in NJ: Bb 33.6%, Bm 8.4%, Ap 1.9%, *Bartonella spp* 34.5% 2
  - CDC questions transmission by ticks
    - 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.”
      https://www.cdc.gov/bartonella/transmission/index.html
  - 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

---

1. Ticks 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) J Clin Microbiol. 2001 Apr;39(4):1221-6. Molecular evidence of Bartonella spp. in questing adult *Ixodes pacificus* ticks in California. Chang CE1, Chomel BB, Kasten RW, Romano V, Tietze N.


STARI (Southern Tick-Associated Rash Illness)

• Transmitted by bite of Lone Star tick (*amblyomma Americanum*)
  o Southern Tick-Associated Rash Illness
    ▪ Also been known as Master’s Disease

• Infectious cause unknown
  o Formerly thought *Borrelia lonestari* cause

• Looks and acts like Lyme
  o EM-like rash: red expanding bully’s eye lesion at bite
    ▪ Appears within 7-10 days, expands to diameter of 3” or more
  o May get fatigue, headache, fever, muscle & joint pains

• Test: none. Diagnosed by symptoms, geography, tick bite

• Treatment: CDC says
  o “In the cases of STARI studied to date, the rash and accompanying symptoms have resolved following treatment with an oral antibiotic (doxycycline), but it is unknown whether this medication speeds recovery.”
  o “…because STARI resembles early Lyme disease, physicians will often treat patients with oral antibiotics”
  o STARI has not been linked to arthritis, neurologic disease, or chronic symptoms

https://www.cdc.gov/stari/index.html
Q Fever

• Q fever
  o Caused by *Coxiella burnetti* bacteria
  o Transmitted most often by inhaling Cb-containing dust or eating or drinking contaminated foods—cattle, sheep, goat reservoirs
    ▪ Other forms of transmission are rare but include tick bites and human to human transmission\(^1,2,3\)
      ▶ CDC does not indicate it’s a tick-borne disease on its tick-borne disease website
      ▶ CDC Public Health Imaging website: *Dermacentor marginatus*, sheep tick, known vector \(^6\)
  o Symptoms
    ▪ High fevers, severe headache, malaise, myalgia, chills and/or sweats, cough, nausea, vomiting, diarrhea, abdominal pain, chest pain
      ▶ May include endocarditis, encephalitis, pneumonia, hepatitis, splenomegaly
  o Tests
    ▪ IFA titers
  o Treatment- 2002-2014 50% of cases required hospitalization
    ▪ Doxycycline, Hydroxychloroquine
    ▪ Chronic Q Fever multiple drugs
  o Case Numbers in 2019: 178 acute, 34 chronic (been on rise)\(^4\)
    ▪ Has been previously weaponized for use in biological warfare and is considered a potential terrorist threat \(^4\)

Rocky Mountain Spotted Fever (RMSF)

- Transmitted by American dog, wood, brown dog ticks
  - Increased new SW cases from brown dog tick
    - *lone star can carry, transmission unsettled: CDC doesn’t say lone star transmission*
      - Publication in *EID*: Lone star transmission by lone star tick in S. Carolina
- 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 reviews
  - Dantas-Torres in Lancet 2007 20%
- **HHS Tick-Borne Diseases Working Group Report to Congress 2020**
  - Improve provider recognition & empiric treatment of Rocky Mountain spotted fever/spotted fever rickettsioses at early stages of illness (e.g., prior to the onset of rash) using doxycycline, including in children younger than 8

---

3 https://www.cdc.gov/rmsf/stats/index.html
Spatial patterns of reported cases of tularemia in the USA from 2011 to 2019 (n=1984) based on data from the Nationally Notifiable Diseases Surveillance System (NNDSS).
Tularemia

- Transmitted by bite of tick or deer fly
  - Ticks that transmit to humans include American dog tick (*Dermacentor variabilis*), Rocky Mountain wood tick (*D. andersoni*), lone star tick (*Amblyomma americanum*)
    - Is NOT transmitted by ticks that transmit Bb (blacklegged)
  - 2 types are tick-borne, Ulceroglandular & Glandular, out of 6 types
  - Infectious cause: bacteria *Francisella tularensis*
  - Sx of TB tuleremia: Skin ulcer where bacteria entered body, may or may not be present. Ulcer accompanied by regional lymph glands, usually armpit or groin

- Other 4 types tularemia
  - Oculoglandular: Bacteria enters thru eye (butchering infected animal)
  - Oropharyngeal: Eating or drinking contaminated water
  - Pneumonic: Breathing dust or aerosols containing organism
  - Typhoidal: Characterized by any combo of general symptoms

- Tests: yes, may vary by exposure type

- Treatments
  - Antibiotics include streptomycin, gentamicin, doxycycline, and ciprofloxacin

- CDC NOTES: people could be exposed as a result of bioterrorism
  - https://www.cdc.gov/tularemia/index.html
Tick-Borne Relapsing Fever 1990-2011

Borrelia species (hermsii most) 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
Ornithodoros Ticks (softbodied)

- Ticks hide in animal burrows
- Found in old cabins in W, caves in TX
- Usually at high altitudes
- Feed at night, short feed
- Can live 10 yrs.+
- Female passes *Borrelia* to eggs

Photo Thanks to Matt Pound USDA Agricultural Research Service, Wikimedia
Pacific Coast Tick Fever/Heartland Virus/ Bourbon Virus

**Pacific Coast Fever**
- Transmitted by Pacific Coast tick (*Dermacentor occidentalis*).
- Caused by *Rickettsia species* 364D (also called *Rickettsia philipi*).
  - One of spotted fever group rickettsiosis (spotted fevers).
- Treatment:
  - Doxycycline treatment of choice for all spotted fever infections.
  - Spotted fevers can range from mild to life-threatening.
  - Provider may order certain blood tests to look for spotted fever infection.
    - Tests can take weeks/Provider should recommend antibiotic tx before results available if thinks SF.
- Symptoms:
  - Most spotted fever patients other than RMSF will have:
    - Eschar (dark scab at bite site), fever, headache rash.

**Heartland Virus**
- Transmitted by bite of infected tick, thought to be *Amblyomma Americanum* (lone star).
  - Arkansas, Georgia, Illinois, Indiana, Iowa, Kansas, Kentucky, Missouri, North Carolina, Oklahoma, Tennessee.
  - Symptoms: fever, fatigue, < appetite, headache, nausea, diarrhea, muscle or joint pain. Many hosp.
  - Testing: Can be performed at CDC only. Health care providers contact their state health dept.
  - Treatment: Supportive care only; Some deaths have resulted.

**Bourbon Virus**
- Transmitted by bite of infected tick, thought to be *Amblyomma Americanum* (lone star).
- Symptoms: fever, tiredness, rash, headache, other body aches, nausea, vomiting also.
  - Low blood counts for cells that fight infection and help prevent bleeding.
- Testing & Treatment: Molecular/serologic blood tests available at CDC, only symptomatic treatment.

---

2. [https://www.cdc.gov/heartland-virus/index.html](https://www.cdc.gov/heartland-virus/index.html)
The controversy simplified is over whether after treatment, Lyme patients who continue to have symptoms do have an active infection, it’s all autoimmune, or combination of both. Some identifiers I have seen used are:

- Chronic Lyme disease (CLD)
- 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
# IDSA vs ILADS Treatment Guidelines

## Table 5: Comparison of Conflicting Guidelines in Lyme Disease

<table>
<thead>
<tr>
<th>IDSA Guidelines</th>
<th>ILADS Guidelines</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>IDSA Guidelines</strong></td>
<td><strong>ILADS Guidelines</strong></td>
</tr>
<tr>
<td>(Wormser et al., 2006)</td>
<td>(Cameron, Johnson, &amp; Maloney, 2014)</td>
</tr>
<tr>
<td>Disease-oriented diagnosis (Ebell et al., 2004)</td>
<td>Clinical diagnosis</td>
</tr>
<tr>
<td><em>Erythema migrans</em> rash alone or physical findings consistent with Lyme disease accompanied by positive two-tier test results</td>
<td>Clinical signs and symptoms with lab tests supportive of the clinical manifestations</td>
</tr>
<tr>
<td>Short-term treatment protocols</td>
<td>Longer treatments may be appropriate</td>
</tr>
<tr>
<td>No persisting infection (do not treat)</td>
<td>Persisting infection may be present</td>
</tr>
<tr>
<td>Retreatment of late-stage presentations: 2x (up to 3x) for Lyme arthritis; only 1x for other late-stage presentations; limited in nature</td>
<td>Retreatment with emphasis on shared medical decision-making and patient education, regardless of type of late-stage presentation and severity of illness</td>
</tr>
<tr>
<td>Disease-oriented outcomes (Ebell et al., 2004)</td>
<td>Patient-oriented outcomes</td>
</tr>
<tr>
<td>Clinical judgment emphasis limited</td>
<td>Clinical judgment emphasis</td>
</tr>
<tr>
<td>Shared medical decision-making is limited or precluded in order to present a more uniform approach to treatment, and the individual patient experience of illness is generally not a factor; No acknowledgment of ILADS guidelines and no recommendation for disclosure to patient; Retreatment, except for Lyme arthritis, is strongly discouraged</td>
<td>Shared medical decision-making is encouraged with patient/physician shared decisions focused on individual patient values, as well as individual patient details and his or her experience of illness; Acknowledgment of IDSA guidelines and recommendation for full disclosure to patient; Retreatment with emphasis on shared medical decision-making coupled with patient education</td>
</tr>
</tbody>
</table>

MyLymeData Patient Registry

- From HHS Working Group Report to Congress 2020 on Registry
  - “The MyLymeData patient registry, like other patient registries, provides crucial information about patients with persistent symptoms associated with Lyme disease and their clinical experiences, including their experiences accessing care and treatment and the obstacles that they frequently face in obtaining appropriate care.”

- Over 12,000 patients enrolled in patient registry

- How long until patients were diagnosed with Lyme
  - 16% <4 months
  - 12% 5-11 months,
  - 17% 1-2 years,
  - 20% 2-6 years
  - 36% 6 years

- Summary
  - 84% not diagnosed within first 4 months

- 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.

https://www.lymedisease.org/mylymedata-lyme-disease-research/
Cases of PTLD (Post Treatment Lyme Disease)

- Studies have shown that Lyme treatment failure rates may range from 10 to 20%\(^1\)

- Some studies indicate that more Lyme patients fail treatment than the 10-20%\(^2\)
  - “When diagnosed early and given appropriate treatment, most Lyme disease patients make a full recovery. However, up to 35% of patients experience chronic, often debilitating, symptoms”

- LD & its sequelae are responsible for significant numbers of school & work absences, & are estimated to cost more than $1 billion/year for healthcare in US
  - “One estimate of cost shows that direct Lyme disease medical costs could represent $1.3 billion each year, with marked increases when therapy fails to return patients to their pre-Lyme disease health status”\(^3\)

- A 2019 study by a statistician at Brown, Allison DeLong\(^4\)
  - 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, & may be as high as 1,944,189 cases
    - Prevalence incudes all cases (new & preexisting) in population over specified time
    - Total number of PTLD cases at Index date 2016 is sum of surviving cases since 1981, or the 36 year prevalence
    - Total at 2020 is the 40 year prevalence

---


\(^2\)Aucott, Rebman, Crowder, & Kortte, 2012

\(^3\)Adrion et al., 2015) HHS Tick-Borne Disease Working Group Report to Congress 2020

\(^4\)Delong A et al “Estimation of cumulative number of post-treatment Lyme disease cases in the US, 2016 and 2020,” BMC Public Health, 2019
Persistent/Chronic Lyme Supported by Scientific Research

- **Persisters**
  - Research on persisters/new antibiotics to eradicate Lyme persisters, new antibiotic protocols including pulsing
    - 2 researchers Y. Zhang, Johns Hopkins & K. Lewis, Northeastern separately investigating persisters & antibiotics
  - What are persisters
    - Some 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)
    - Disease can flare up again when treatment stops

- **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 Case Definition for Lyme

- CDC statement on Surveillance Case Definitions
  - Surveillance case definitions establish uniform criteria for disease reporting and should not be used as the sole criteria for
    - establishing clinical diagnoses
    - determining the standard of care necessary for a particular patient
    - setting guidelines for quality assurance or
    - providing standards for reimbursement. ¹

- What has been happening in practice with Lyme Surveillance Case Definition
  - Doctors are inappropriately requiring CDC surveillance criteria to diagnose
  - Doctors are using it to determine the standard of care
  - Insurance companies are using criteria for reimbursement

- Up until 2022, Lyme Surveillance Guidelines used were 2017 version

- CDC now using 2022 Lyme Disease Surveillance Guidelines for all cases in 2022
  - On the new 2022 Surveillance case Definition²
    - "This CSTE case definition is intended solely for public health surveillance purposes and does not recommend diagnostic criteria for clinical partners to utilize in diagnosing patients with potential Lyme Disease."
    - New guidelines have more choices of confirmatory lab evidence including culture, nucleic acid amplification test (NAAT), immunohistochemical assay in addition to the modified & standard two tier for some case classifications with continued use of hi-incidence or low incidence jurisdictions
    - Time will determine if changes will help in the areas of Lyme treatment & diagnosis

Differential Diagnosis

- Lyme can mimic other diseases/conditions
  - MS
  - ALS
  - CFS
  - FM
  - Rheumatoid arthritis
  - Alzheimer’s
  - Parkinson’s
  - Lupus
  - Autism
  - ADD/ADHD
  - Psychiatric conditions

- Doctors need to see if Lyme is causing these symptom clusters and treat for Lyme if condition is caused by this underlying infection

Photo Thanks B. Fallon, MD, Columbia University
Lyme & Kids

Blacklegged/deer ticks  Lone star ticks

From LDA’s Lyme Disease Is No Fun! Let’s Get Well, Photo Courtesy: Jim Occi, PhD, LDA Professional Advisory Board
Columbia University Studies


- Children with Lyme disease had significantly more cognitive and psychiatric disturbances.
- Cognitive deficits were still found after controlling for anxiety, depression, and fatigue.
- Lyme disease in children may be accompanied by long-term neuropsychiatric disturbances, resulting in psychosocial and academic impairments.
- Regarding depression
  - parents indicated that 41% of children with LD had suicidal thoughts
  - 11% had made a suicide gesture.


- Documents IQ improvement of 22 points in a 16-year-old after IV treatment for Lyme disease.
Why Do Children in School Have Problems?

• Lyme can affect all the systems of the body
• Its signs and symptoms are varied.
• Often children exhibit problems associated with Lyme, especially behavioral and mood changes, that go unrecognized by districts.
• At times, children may be improperly classified, labeled neurologically impaired or emotionally disturbed when perhaps a classification including "other health impaired" might be more appropriate to address the medical problems triggering the neurologic and/or psychiatric problems that stem from Lyme.
• Children may be identified with attention deficit disorder, medicated for those symptoms, and no cause is ever sought.
Why Schools Question Lyme

• Fluctuations in, and the variety of, symptoms
  ▪ Lyme symptoms can vary from day to day, hour to hour.

• Serious sleep disturbances may cause a child to oversleep in the morning because of difficulty falling asleep at night.

• Executive functioning may be impaired
  ▪ the child may have difficulty organizing day or life.

• Recurrent short-term memory, concentration and recall problems, mental confusion, and exhibition of dyslexic type symptoms interfere with the learning process.

• Forgetting books and homework assignments
  ▪ especially in a middle or high school
A 1992 CDC/NJ Department of Health study in NJ of 64 school children with Lyme showed that:

- the median duration of Lyme at time of interview was 363 days;
- the median number of days the illness was said to have significantly affected normal activities was 293;
- the mean number of total school days lost was 140;
- the mean duration of home instruction, 153 days.

Only 26% of children under study were said to have fully recovered.[ii][4]

The direct medical costs per case incurred by 54 case-patients:

- totaled $5.2 million, $8.7 million in CPI adjusted 2013 dollars.\(^2\)
- The mean estimate was $96,569 ("274,412-2013); and
- costs of $100,000 ("166,891-2013) or greater were incurred by more than 1/5 of children.
- Some indirect costs were assessed totaling about $15,000 (" 25,034- 2013) due to lost time caring for patient and parents’ lost time transporting children to medical treatment.”[i]

Perhaps the greatest costs incurred by the study children were the social costs of the illness and its treatment. Schooling and extracurricular learning activities were seriously interrupted for most children. Often, children spent large blocks of time as semi-invalids, isolated from social groups and missing out on cultural, sports and social activities. School performance of nearly all children fell, sometimes drastically, and in several instances was said to interfere with selection by colleges and universities.” Study quote by a superintendent

1 US House Energy & Commerce Health Subcommittee, Testimony on HR 610, November 20, 2013, Smith, Patricia V. Washington, DC

2 Department of Labor & Statistics CPI calculator

Student Evaluations

- To ensure problems are not organically produced by Lyme disease, districts, parents, & doctors need to carefully evaluate any child with a history of Lyme experiencing
  - neurologic
  - psychiatric
  - attention deficit problems

- The bacteria causing the disease can enter the central nervous system less than a day after a tick bite

- Additionally, the role of co-infections, diseases transmitted by the same ticks, needs to be examined
The suggestions below are based on my years of experience as a Board of Education Member/President, Child advocate, LDA President, Parent of child with Lyme, Lyme Educator, Teacher

- Children with Lyme experience “transitory learning disabilities” since they may vary year to year, month to month, even day to day.

- Possibilities must be built into an IEP, since conditions change so frequently

- A child may require home instruction, special instruction, be in a regular classroom, or may be on home instruction and in school part time at the same time.

- IEPs often need to contain provisions for instruction over holidays, weekends and the summer, since teachable moments are unpredictable.

- Provisos need to be made for students on long-term home instruction to attend school for special events, lunch, or even for a class visit just to break up the isolation from peers.

- Often students can only take core course subjects because they need to conserve all their strength just to get out of bed and complete those subjects.

- Quality vs. quantity- Students who have the ability to take honors or advanced placement courses are often discouraged from doing so.
  - They need to be supported in that choice and permitted to demonstrate a mastery of the curriculum without having to have the extras work.
IEP/504 Possible Modifications

• Oral tests
• Break up instructional periods
• Extend assignment times
• Extend test times
• Testing over several day period
• Tape books/lectures (now have internet)
• Access textbooks for the blind
• Assignment reinforcement
• Extra set of books
• Student needs to move around
• Address sound/sensitivity problems, change seating
• Sometimes, quality vs. quantity, esp. w. honors, AP
• Let go to nurse
• Shorten school day
• Home instruction
School/District Policy Revisions

- Activities/attendance policies - often forbid attendance at activities after or during an absence, but the situation involving a child with a chronic condition like Lyme disease does not fit into any existing paradigm
  - a child may be out of school for extended periods of time, although he or she may be capable of attending a particular event.
    - Absences of months to years often make a student a social outcast and recluse.

- Homework policies - set a length of absence required before homework is sent home. Because of the unpredictability of symptoms and frequent and sometimes short absences of students with Lyme disease homework needs to be supplied without any waiting period.

- Outdoor class trip policies and procedures should also include information about the dangers of Lyme disease, thus protecting the staff and children from unnecessary exposure to the disease and the district from unnecessary expense and/or litigation.
LDA Resources

- **Lyme Disease Is No Fun! Let’s Get Well**
  - Written, edited, by 2 with LD
  - for 8-12 yr. olds with LD
  - Published by LDA
  - Author Amy Tan wrote cover note

- **The ABC’s of Lyme Disease**
  - Published by LDA esp. for parents & educators

- **Best Practices in School Health** manual, Lyme Disease
  - Pub. By Federal News Service
  - Interviews of Pat Smith

- **School Leader**, 
  - Pub. by NJSBA
  - The Effects of Lyme Disease on Students, Schools, and School Policy

- **How A Tick Can Make You Sick**, free online PowerPoint for schools

- **National Association of School Nurses**
  - You Can Make a Difference to a Child by Reducing Risk of Lyme Disease March 2010

- On LDA website prevention video (UMDNJ)
  - TickLES (Tick Learning and Education for Schools)
    - for grades 4-8.

- **LymeAid 4 Kids Fund (LDA)** financial aid for children w/o insurance coverage

  Go to www.LymeDiseaseAssociation.org
LEGISLATION IN CONGRESS
Hope to have introduced into this current Congress

LAST CONGRESS: May 27, 2021 —Congressman Christopher Smith (NJ-4-R) introduced into House “Children Inflicted by Lyme Disabilities Act 2021,” or “CHILD Act 2021

- Co-sponsors were:
  - Lyme Caucus Co-Chair, Rep. Henry Cuellar (TX-28-D)
  - Lyme Caucus Member Rep. Bill Posey (FL-8-R)
  - Rep. Josh Gottheimer (NJ-5-D)
  - Rep. Brian Fitzpatrick (PA-1-R)

- LDA initiated & helped to write bill

- **Purpose:** “To amend the Individuals with Disabilities Education Act (IDEA) to recognize more clearly that Lyme disease can cause disabilities that affect the education of children and to enhance educational services and related services for children with Lyme disease and other tick-borne diseases and for other purposes.”

  - Will amend IDEA by adding “including Lyme disease and other tick-borne diseases” under “other health impairments.”

- Was not brought up for vote in that Congress

THIS CONGRESS: Planning to have bill reintroduced

HHS Working Group (2017-2022)

- Had been govt. Lyme working group (WG) in DC for years before public HHS WG created
  - But only Govt. Agencies were involved in decision making and not done in public
  - Worked with Congressmen Gibson & Smith to get WG created under FACA (Federal Advisory Committee Act). Agencies did not want it

- Advocate coalition worked to get language needed into bill (Gibson version & language into 21st Century Cures)
  - I did final negotiations. Govt. did not want to give us diversity of viewpoint. We had 6 iterations of changes during our negotiations. I got diversity in. We got it passed in 2016
  - Patients now had an opportunity to sit at the table in Washington, DC
    - To provide input into significant government research focusing on understanding mechanisms of persistent symptoms
    - To provide input into a test that provides accurate information as to whether Lyme is present & into new treatment modalities
  - Discussion takes place with advocates, federal members, physicians & researchers also at table
  - Candidates for WG go through screening process for conflicts
    - Held in public under FACA
    - Diversity of scientific disciplines and viewpoints are key in this legislation
  - WG made recommendations to Congress every 2 years

L: 2018 swearing in
R: Members Pat Smith & Scott Cooper, CMS
• **Recommendation 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.

• **Action taken by NIH 2019:** NIH STRATEGIC PLAN FOR TICKBORNE DISEASE RESEARCH

  In developing this strategic plan, as recommended by the TBDWG Report, NIH sought input from the research and medical communities, patient advocacy groups, pharmaceutical industry, and general public.
  - The Lyme Disease Association submitted input to the NIH on a strategy

LymeX: HHS & Cohen Foundation

LymeX: public private partnership between
- Health & Human Services (HHS) and Steven & Alexandra Cohen Foundation
- Largest public-private partnership in world
- Modeled after another such partnership KidneyX, very successful

LymeX Mission
- Accelerate Lyme Innovation progress and strategically advance tick-borne-disease solutions in direct collaboration with Lyme patients, patient advocates, and diverse stakeholders across academia, nonprofits, industry, and government
  - I have been involved in some aspects
- Goal: Accelerate Development of Next-Gen Diagnostics
  - LymeX prize challenges encourage rapid, cross-sector, patient-centered diagnostic innovations. These challenges will drive creators, industries, and academia toward breakthroughs in more accurate Lyme diagnosis, helping make next-gen diagnostics available more quickly.
  - Allows prize competitions for aspects of research, such as testing

May 2022: competition to accelerate the development of Lyme diagnostics
- Phases 1- $1M (judging panel recommend up to 10 winners) [https://www.lymexdiagnosticsprize.com/](https://www.lymexdiagnosticsprize.com/)
- $10M anticipated total prize pool across 3 phases
- Technical clinical scientific experts will submit innovative detection methods to advance Lyme diagnostics
- Goal of competition to develop diagnostics to be submitted to FDA for review—tests to detect active infection

LymeX funding- for unknown reasons, in 2021, this was not included in Congressional appropriations.
- Partnership still operational but no new funding from Government provided

PA Lyme Legislation

- SB-232 bill (Sponsor Sen. Michele Brooks; Mercer Co.) (Tick Removal in Schools)
  - Passed Senate 49-1 April 26, 2023¹

- Bill Requirements
  - School nurse, school physician, designated employee of school entity shall remove tick from student in accordance with Sec. Health guidelines
    - Requires parental notification in writing about tick removal
    - Requires symptom information about Lyme
    - Includes date of tick removal
    - Recommends seeking prompt medical treatment (legislation lists items to include such as sx)
  - School required to preserve tick
    - Shall provide information on how to send tick for testing
    - For parent/guardian (if want to) to send tick to East Stroudsburg University for Free TBD testing
    - School has option to send tick for testing directly to above lab for free basic panel tick test
    - School shall immediately provide original results to parent/guardian
      - Shall not make copy of results or include in school medical record
      - May note diseases present in tick (no personal ID) to compile data of diseases around school
  - Requires Secretary of Health
    - To publish guidelines on the foregoing provisions of bill

¹ https://www.legis.state.pa.us/CFDOCS/Legis/RC/Public/rc_view_action2.cfm?sess_yr=2023&sess_ind=0&rc_body=S&rc_nbr=62
https://www.legis.state.pa.us/cfdocs/billinfo/billinfo.cfm?year=2023&Ind=0&Body=S&type=B&bn=232

Graphic: From LDA’s LymeR Primer
Can We Escape Ticks?

- Scientists have discovered
  - Globally distributed seabird ticks, *Ixodes uriae* \(^3\)
  - Ticks contain 4 new arboviruses \(^1\) – closest relatives found in N. Hemisphere
    - infesting colonies of King, royal & rockhopper penguins on sub-Antarctic Macquarie Is.

- In Subantarctic- southern hemisphere just N of Antarctic Circle contains Campbell Is. & îles Crozet (Fr. Southern & Antarctic Lands)
  - "The zoonosis Lyme disease is caused by the spirochaete *Borrelia burgdorferi*, which is carried by sea birds transmitted by *Ixodes* ticks. It has been found through DNA analysis in ticks on the Campbell Islands and the îles Crozet. King penguins on the îles Crozet have antibodies to *B. burgdorferi.*" \(^2\)

4. Photo thanks James Occi, PhD, Rutgers University Seabird tick M,F
Engorged Nymphal Amblyomma Tick

- 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 Piroplasms 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
Australian Snake with Ticks 2019

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

Courtesy: Gold Coast and Brisbane Snake Catcher 2019
WANTED
DEAD OR ALIVE
IXODES SCAPULARIS
A.K.A. DEER TICK
FOR TRANSFER OF LYME DISEASE
KNOWN HIDEOUT: WOODED AREAS
IN NORTHEASTERN UNITED STATES
$1,000
REWARD
Patrolling the Rio Grande for stray “ticky” livestock, exotic livestock & deer.

Strays are captured, “scratched” for ticks, treated & returned to Mexican owners for the cost of feed.
Cattle are inspected, then run thru spray boxes or submerged in dipping vats charged with Co-Ral
Why Rhinos Have It Easy

The ticks are especially good today...

PREVENTION

Graphic thanks: James L. Occi, PhD
Who Protects Humans?

- Tuck pants in socks
- Long-sleeved shirts
- Wear light colored clothing
- Wear shoes & socks
- Wear hat and tuck in long hair
- Full Body tick checks-Most important
- Remove ticks promptly & properly or risk of infection increases
- After being outside, put clothes in dryer for at least 35 minutes to kill any ticks

Special tick prevention clothes
- Rynoskin™ [https://rynoskin.com/]
  - Chemical free
  - Wear under clothing
  - Long underwear type, tight weave, tight cuffs
  - Resistant to mosquitoes- tested by insect scientists at NC State University
  - Company did tick testing & says no ticks able to penetrate, also same for No-See-Um testing

- Insect Shield® Repellent Apparel [https://www.insectshield.com/]
  - Approved vendor of US Army
  - Clothing lasts up to 70 washings
  - Insect Shield: 1st-ever EPA registered insect repellent clothing & gear (tick, mosquito, ants, flies, chiggers, midges)
  - Permethrin treated at time of manufacture clothing to buy or send your clothes to them to treat

Sprays for clothes, sprays for skin–Be informed use EPA [https://www.epa.gov/insect-repellents/find-repellent-right-you]

- LDA does not make product recommendations but cautions
  - Never use spray designated for clothes on skin
  - Always read manufacturers directions and cautions
  - Be especially careful if considering for children
  - Some “natural” products are being developed, you need to investigate
Current Lyme Vaccine Trial – Valneva-Pfizer

Valneva French biotech Vaccine 12.2016 Vaccine trial FDA Phase 1

- Based on same core concept as FDA-approved LymeRix
  - Works by injecting people with OspA, outer surface protein, of *Borrelia*
    - Taught body’s immune system to recognize bacteria & launch attack if shows up after tick bite
    - LymeRix vaccine was withdrawn citing “poor sales”
    - Controversy surrounded arthritic & neurologic issues some vaccine recipients said they had
    - Class action lawsuit also ensued
- Now 6 different types of OspA in the new Valneva-Pfizer vaccine
  - Valneva based vaccine on all different OspA to cover US/European *Borrelia*
- 2017 Valneva received FDA Fast Track Designation for VLA15
- 2020–Valneva & Pfizer announced collaboration on the Valneva Lyme vaccine
- 2022–Phase 2 trial showed value in adding a third dose of vaccine
  - Phase 2 clinical trial for pediatrics (aged 5-17) is ongoing
  - 2022– Aug. 8, Valneva & Pfizer: Stage 3 Study, 5+ yrs. 6,000 participants, US & Europe

Concerns

- We have no knowledge that issues brought forth from last vaccine discussed/addressed
- Have seen no evidence of public discussion that there even were issues and how addressed
- Manufacturer has not reached out to stakeholders such as the Lyme community or to doctors who were involved during first vaccine for input to our knowledge

file:///C:/Users/Pat%20Smith/Downloads/2018_03_29_Valneva_World_Vaccine_Congress_PR_EN.pdf
Pfizer Shuts Down Part of Lyme Vaccine Trial

- Pfizer & Valneva stop testing half of US patients in vaccine trial
- Martha’s Vineyard & other sites affected
- Can delay vaccine time to approval
- Pfizer reported that nearly half of the study’s participants will be removed from the trials due to good clinical practice (GCP) violations by third-party facilitators.
- No other information after Feb. announce was available that we could find
Moderna MRNA Lyme Vaccine Development

- mRNA vaccines contain messenger RNA (mRNA), single stranded-RNA
  - mRNA-based COVID vaccines were
    - first Moderna products to be approved by FDA
  - Now Moderna has 2 mRNA Lyme vaccine candidates
    - designed to create antibodies for most common Lyme bacteria species:
      - mRNA-1982 for *Borrelia burgdorferi* in US
      - mRNA-1975 for 4 “major” *Borrelia* species in Europe

[Borrelia burgdorferi bacteria photo courtesy Dave Dorward, PhD, Rocky Mountain Lab, NIH]
Getting Rid of Ticks

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

*M. anisopliae* on female *I. scapularis*

Met52 (Novozymes Biologicals Inc.).

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

Photo used with permission from Kirby Stafford, CT Agricultural Experiment Station)
Oral Vaccine for Wildlife

- **US Biologic**: Conditional USDA license oral Lyme vaccine for mice
  - USDA: “For the vaccination of mice against Borrelia burgdorferi or Lyme Disease.”
    - *Meets emergency condition & demonstrated safely*

- **Called Borrelia Burgdorferi Bacterin**
  - Spray coated onto pellets that (wildlife) mice consume
  - Lyme Shield Station for timed pellet application or a broadcast application
  - Product is controlled biologic
    - Application requires licensed pest management specialist or licensed field biologist
New Acaracide Researched to Kill Blacklegged Ticks

• Concerns about many acaracides/pesticides are environmental problems, harm beneficial insects

• *Nature* July 2022¹, researchers looking at a possible new natural pesticide

• Balsam fir (*abies balsamea*) needles & essential oil from them

• Reason:
  - *I.scapularis* (blacklegged) ticks winter over under leaf litter
  - Litter allows nymph/larvae to have 80% survival rate over winter
  - These ticks can survive under litter well below 0° C (32°F)
  - Discovered these ticks did not survive well under balsam fir
    - Low temperatures may also aid in killing process with these substances

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.
Thanks & Questions

Thanks to:

- Bonnie Miller, RN, CSN, Med
- Jennifer Kaufman
- Souderton School District
- All who helped to provide the program
- Attendees for taking time to learn about Lyme & TBD

Source: GIS Geography.com