



LDA

### Lyme Disease Association

Funding research projects from coast to coast

- > Is a national, all-volunteer 501(c)(3) corporation. Contributions are tax deductible to the extent allowed by law.
- > Contributes 98 cents of every dollar donated to programs.
- > Provides input for federal and state Lyme legislation.
- > Helps children with Lyme get a proper education.
- > Sponsored first national medical conference focusing on Lyme disease in children & adolescents.
- > Partnered with Time for Lyme & Columbia University to open the Lyme & Tick-Borne Diseases Research Center to study chronic Lyme.
- > Has LymeAid 4 Kids for kids w/o insurance.

### Affiliates/Chapters/Coalitions:

- Time for Lyme, TFL (CT)
- California Lyme Disease Association, (CALDA)
- Lyme Disease Network of New Jersey, Lymenet.org
- Lyme Association of Greater Kansas City, LAGKC (KS/MO)
- Lyme Disease Association of Southeastern Pennsylvania
- NYC Lyme Disease Support Program (NY)
- Texas Lyme Disease Association, TLDA (TX)
- Florida Lyme Advocacy, Inc.
- Harford Co. LDSG, Inc. (MD)
- Minnesota Lyme Action Support Group
- Oregon Lyme Disease Network
- Mid Shore Lyme Disease Association, Inc. (MD)
- Lyme Disease Association Southeastern Florida Chapter
- Lyme Disease Association Eastern Connecticut Chapter
- Lyme Disease Assn. Corning/Fingerlakes Area Chapter (NY)
- Lyme Disease Association, Cape Cod Chapter (MA)
- Lyme Disease Association, Pennsylvania Chapter (LDAPAC)
- Lyme Disease Association, Rhode Island Chapter, LDARIC
- Stop Ticks on People, STOP (NY)

### Other suggested resources:

- <http://Columbia-Lyme.org>
- <http://www.LymeNet.org>
- <http://www.IGeneX.com>
- <http://www.ILADS.org>

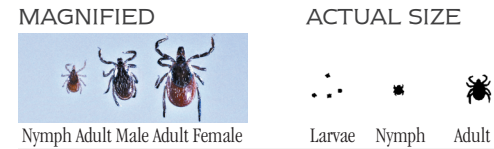
### Lyme & Pets

- > Dogs, cats, horses, and cows can get Lyme disease and other tick-borne diseases and can be tested.
- > Perform tick checks to protect your pets.
- > Use veterinarian recommended products.
- > Dogs - symptoms are unexplained lameness, fever, lethargy, loss of appetite.
- > Cats - symptoms are excessive sleep, fever, appearing arthritic or lame, stop eating.

## Tick Identification Guide

***Ixodes scapularis*** (deer tick)  
 Found in Northeast & Upper Midwest  
 Transmits agents of: Lyme, babesiosis, anaplasmosis (aka human granulocytic ehrlichiosis), Powassan encephalitis, tick paralysis, tularemia, bartonella.

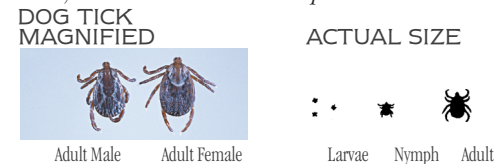
*Ixodes scapularis* have been shown to carry ehrlichiosis (HME), but to date, transmission is still in question.



***Amblyomma americanum*** (lone star)  
 Found throughout the United States  
 Transmits agents of: human monocytic ehrlichiosis, STARI (Southern tick-associated rash illness), tularemia, tick paralysis, Rocky Mountain spotted fever.

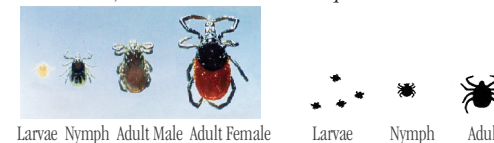


***Dermacentor variabilis*** (American dog)  
 Found throughout the United States  
 Transmits agents of: Tick paralysis, Q fever, Rocky Mountain spotted fever, tularemia, human monocytic ehrlichiosis.  
*Although a small percentage of dog ticks carry the Lyme bacterium, no transmission has been proven.*



***Dermacentor andersoni*** (wood)  
 Found in Rocky Mt. States & SW Canada  
*Looks similar to American dog tick (above)*  
 Transmits agents of: Rocky Mountain spotted fever, tularemia, Colorado tick fever, tick paralysis.

***Ixodes Pacificus*** (western black legged)  
 Found in West  
 Transmits agents of: Lyme, babesiosis, anaplasmosis (aka human granulocytic ehrlichiosis), bartonella.  
*Ixodes pacificus* have been shown to carry ehrlichiosis (HME), but to date, transmission is still in question.



Endorsed by:



International Lyme & Associated Diseases Society  
 A Medical and Research Organization for Health Science Professionals  
[www.ILADS.org](http://www.ILADS.org)

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 & Robert S. Lane, PhD

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## Lyme R Primer



Learn About Lyme & Other Tick-Borne Diseases

- Lyme Disease
- Anaplasmosis
- Babesiosis
- Ehrlichiosis
- Bartonella
- Rocky Mountain Spotted Fever
- Tularemia



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 (LDA)

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 Website: [www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org)

## Tick Removal

- > Do not burn or use any substance on tick.
- > Do not grasp, squeeze or twist body of tick.
- > Grasp tick close to skin with tweezers.
- > Pull tick straight out.
- > Use antiseptic on skin.
- > Disinfect tweezers.
- > Wash hands thoroughly.
- > Always see a physician for possible diagnosis, testing and treatment.
- > Improper tick removal increases chances of infection.

## Tick Testing for Lyme, Babesia, Anaplasma, Bartonella & Ehrlichia

- > Save tick alive if possible.
- > Place in airtight container or zip lock bag.
- > Put in with moist cotton ball (no alcohol).
- > Send with check to tick-testing lab.

Tick testing labs include:

**IGeneX Labs, Palo Alto, CA (800) 832-3200**

**MDL, Mt. Laurel, NJ (877) 269-0090**

**NJ Labs, New Brunswick, NJ (732) 249-0148**

**Check your state/local health department**

## Prevention

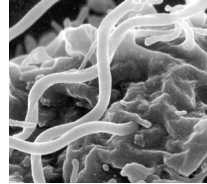
- > Perform frequent, thorough tick checks.
- > Wear light-colored clothes.
- > Tuck pants into socks.
- > Put clothes in dryer for 30 minutes to kill ticks.
- > There are products containing DEET for skin.\*
- > There are products containing Permethrin for clothes.\*
- > There are clothes which protect against ticks\*

www.rynoskin.com

\*Always follow manufacturer's directions. The LDA does not make specific product recommendations or grant any warranties.

## Get the Facts

- > You can contract many tick-borne diseases simultaneously from the same tick bite.
- > You can test negative and still have Lyme disease.
- > The longer a tick attachment, the greater risk of disease transmission.
- > According to the CDC surveillance criteria, an erythema migrans (EM) rash in an endemic area, means Lyme disease – in a nonendemic area, rash requires a positive test.
- > CDC criteria are for surveillance purposes, not diagnosis.
- > Not everyone who contracts Lyme disease gets a rash.
- > Lyme is a clinical diagnosis based on a patient's symptoms, history and examination.
- > Lyme bacterium can cross the placenta into the fetus, can cause death of the fetus, and its DNA can be found in breast milk.
- > Lyme patients often get worse before getting better on treatment (Jarisch-Herxheimer reaction).
- > Lyme symptoms can develop days or months after a tick bite.
- > Lyme can cause death occasionally.



A scanning electron microscope image of *Borrelia burgdorferi* penetrating a human B cell (in vitro), at a magnification of approximately 89,000. Photo Credit: David W. Dorward, Ph.D. NIH Rocky Mountain Labs, MT.

## Lyme Bacteria: *Borrelia burgdorferi*

- > Go intracellular & hide; go dormant and also mutate.
- > Become sequestered in difficult to penetrate sites (central nervous system, joints, eyes).
- > Use body's own cells to shield them.
- > May have other than spirochete forms such as L-form cell wall deficient) and cystic form (giant L-body) which are not readily treatable with antibiotics and whose functions are not clearly understood.
- > Have been found in patients after long-term treatment.
- > May be associated with a neurotoxin.

## Lyme Signs & Symptoms

EM (bull's eye) rash at bite site (less than 50%), other types of rashes, rash at other than bite site, flu-like illness. **Musculoskeletal:** joint/muscle pain in feet, swelling in toes, balls of feet, ankle pain, burning in feet, shin splints, joint pain or swelling, stiffness of the joints, neck or back, muscle pain or cramps that may migrate, neck creaks and cracks, neck stiffness, TMJ. **Reproductive:** testicular pain / pelvic pain, menstrual irregularity, 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 or valve prolapse. **Neurological:** twitching of the face, eyelids or other muscles, headache, tingling, numbness, burning or stabbing sensations, facial paralysis (Bell's palsy), dizziness, poor balance, increased motion sickness, light-headedness, wooziness, difficulty walking, tremor, confusion, difficulty in thinking or with concentration or 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, buzzing or ringing in ears, ear pain, deafness, seizure activity, white matter lesions, low blood pressure. **Neuropsychiatric:** mood swings, violent outbursts, irritability, depression, disturbed sleep (too much, too little, early awakening), personality changes, obsessive/compulsive disorder, paranoia, panic/anxiety attacks, hallucinations. **Gastrointestinal:** nausea or vomiting, difficulty eating, change in bowel function (constipation, diarrhea), gastritis, abdominal cramping, irritable bladder or bladder dysfunction, cystitis. **Other:** fever, sweats, or chills, weight change (loss or gain), fatigue, tiredness, hair loss, swollen glands, sore throat, difficulty swallowing, swelling around the eyes.

## Tests for Tick-Borne Diseases

### Lyme Disease Tests:

- > **Antibody Response** - tests only the level of antibody produced by your body in response to the disease. Includes: ELISA, C6Peptide, IgG and IgM Western Blots. During the first year after a tick bite, less than 65% of patients produce antibodies, and they may not last. By year two, less than 50% of patients still have an antibody response. Antibody response tests are most effective starting 4-12 weeks after a tick bite, and accuracy rates vary considerably. Antibody levels may be negative after inadequate treatment with antibiotics.
- > **Antibody Capture** - an antibody test with the same problems as the test above.
- > **Culture** - grows actual organism. Difficult to do, but when positive, it is considered confirmatory for Lyme.
- > **Antigen Capture** - a highly defined antibody captures pieces of the Lyme organism. Actually checks for the presence of a piece of Lyme bacteria and supports the diagnosis of active infection. Includes LDA (Lyme Dot Antigen Assay for Urine and CSF).\*
- > **Polymerase Chain Reaction (PCR)** - checks for the actual presence of the genetic material (DNA/RNA) of the organism. If the sample contains any DNA/RNA, the PCR is highly accurate. Can be performed on all tissues of the body.\*

### Babesiosis, Bartonella & Ehrlichiosis Tests:

- > **Babesia** - an IFA (IgG & IgM), FISH (Flourescent in-situ Hybridization) and PCR may be ordered.\*
- > **Ehrlichia** - an IFA and PCR for *E. equii* (HGE) and/or *E. chaffeensis* (HME) and PCR for HGE and HME are available.\*
- > **Bartonella henselae** - an IFA and PCR are available.\*

\* These tests were developed and performance characteristics determined by independent labs. They have not been cleared or approved by the FDA; however, the FDA has determined such clearance is not necessary. They are designed for clinical purposes and should not be regarded as investigational or for research.

## Other Tick-Borne Diseases

One tick bite can give you many different diseases at the same time (co-infections). Treatments vary, examples provided as information only.

- > **Babesiosis** - Malaria-like illness caused by a protozoan, *babesia microti*, WA-1, MO-1, sometimes fatal in the elderly or those with no spleen. May be more severe in patients with coexisting Lyme. Symptoms include fever, chills, fatigue, headache, muscle pain, sweats and anemia. Treatment may be atovaquone with azithromycin or clindamycin and oral quinine.
- > **Bartonella-illness** - disease caused by *Bartonella henselae* or perhaps other spp. that can be transmitted either by a cat bite or scratch or a tick bite. When tick-borne, atypical presentations may result including visual problems, headaches, significant lymph node enlargement, resistant neurological deficits, and the new onset of a seizure disorder. Diagnosis is made by acute and convalescent antibody titers (IFA) and by PCR (DNA) analysis. Treatment may be tetracycline and quinolone.

> **Ehrlichiosis** - Human monocytic ehrlichiosis is caused by *Ehrlichia chaffeensis* (symptoms below Anaplasmosis).

> **Anaplasmosis** - Formerly human granulocytic enrlchiosis, is caused by *Anaplasma phagacytophilum*.

Symptoms of both ehrlichiosis and anaplasmosis include fever, malaise, headaches, chills, severe muscle aches, vomiting, anemia, lung infection, decreased white blood cells and platelets, elevated liver enzymes, seizures, encephalopathy, meningitis, confusion, ataxia, and cranial nerve palsy. Co-infection with Lyme can cause more severe symptoms. Death can result. Treatment is with doxycycline.

> **Rocky Mountain Spotted Fever** - Caused by the bacterium *Rickettsia rickettsii*. Symptoms include headaches, myalgia, and a characteristic rash usually beginning on wrists, ankles, palms and soles. Treatment is tetracycline.

> **Tularemia** - Caused by a bacterium, *Francisella tularensis*, Symptoms include headache, chilliness, vomiting, aching pains, fever. Infection site develops into an ulcer, swollen glands, sweating, weight loss, debility. Treatment, streptomycin or gentamicin.

> **Powassan Encephalitis** - Caused by a flavivirus, Powassan (POW), transmitted by the *Ixodes cookei*, *Ixodes marxi*, *Ixode spinipalpus*, and *Dermacentor andersoni* ticks. May possibly be transmitted by *Ixodes scapularis*. Symptoms usually begin suddenly 7-14 days following infection, and include headache, fever, nausea and vomiting, stiff neck, and sleepiness. Later, breathing distress, tremors, confusion, seizures, coma, paralysis, and sometimes death can occur.

> **Q Fever** - Caused by *Coxiella burnetti*. Acute symptoms include hepatitis and pneumonia or chronic endocarditis.

## Lyme Disease & Education: It's the Law

All states have their own special education laws; two federal laws protect students with Lyme disease and supercede state code and regulations. Individuals with Disabilities Education Act (IDEA) covers all students who have some form of disability. Students with chronic Lyme may fit several different categories depending on how severe the disease has impacted the child's ability to profit from regular education. Read your state's special education code to become an active participant in the decision making process for your child. Many states have slightly different categories and definitions than those given in IDEA. Remember IDEA supercedes all state special education laws except when the state law is more protective of your child's rights or offers more services.

Nationally, students with chronic Lyme often are classified and have an IEP, or they may qualify under Section 504 for a 504 plan. Anyone who has a physical or mental impairment that substantially limits one or more major life activities (e.g. walking, learning, working) or has a record of having a substantial impairment or is regarded as having a substantial impairment is entitled to placement in the regular educational environment with the use of supplementary aids and services unless it is demonstrated that education in the regular environment cannot be satisfactorily achieved. Locally, check state law and school district special education policies. New Jersey law requires school districts to annually inservice staff members who teach students with Lyme disease. For more information, go to [www.504idea.org](http://www.504idea.org) and [www.idea.org](http://www.idea.org)