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About Lyme Disease

Lyme disease is a bacterial infection primarily transmitted by Ixodes ticks, also known as deer ticks or blacklegged ticks. These tiny arachnids are typically found in wooded and grassy areas. Although people may think of Lyme as an East Coast disease, it is found throughout the United States, as well as in more than sixty other countries.



The Centers for Disease Control and Prevention estimate that 476,000 people are diagnosed with Lyme disease in the US every year. However, because diagnosing Lyme can be difficult, many people who actually have Lyme may be misdiagnosed with other conditions. Many experts believe the true number of cases is much higher.

Lyme disease affects people of all ages. The CDC notes that it is most common in children, older adults, and others such as firefighters and park rangers who spend time in outdoor activities and have higher exposure to ticks.



DO YOU HAVE LYME DISEASE?

Only 25% of Lyme patients recall a tick bite.

[CHECK YOUR SYMPTOMS](#)

Lyme disease is caused by a spirochete—a corkscrew-shaped bacterium called Borrelia burgdorferi.

LymeDisease.org has developed a Lyme disease [symptom checklist](#) to help you document your exposure to Lyme disease and common symptoms for your healthcare provider. You will receive a report that you can print out and take with you to your next doctor’s appointment.

What Is Lyme Disease?

Lyme disease is caused by a spirochete—a corkscrew-shaped bacterium called Borrelia burgdorferi. Lyme is called “The Great Imitator,” because its symptoms mimic many other diseases. It can affect any organ of the

body, including the brain and nervous system, muscles and joints, and the heart.

Patients with Lyme disease are frequently misdiagnosed with chronic fatigue syndrome, fibromyalgia, multiple sclerosis, and various psychiatric illnesses, including depression.

Misdiagnosis with these other diseases may delay the correct diagnosis and treatment as the underlying infection progresses unchecked.



SCAN THE QR CODE TO CHECK YOUR SYMPTOMS

How Do People Get Lyme Disease?

Most people get Lyme from the bite of the nymphal, or immature, form of the tick. Nymphs are about the size of a poppy seed. Because they are so tiny and their bite is painless, many people do not even realize they have been bitten.

Once a tick has attached, if undisturbed it may feed for several days. The longer it stays attached, the more likely it will transmit the Lyme and other pathogens into your bloodstream.

If pregnant women are infected, they sometimes pass Lyme disease to their unborn children and, while not common, stillbirth has occurred. Some doctors believe other types of human-to-human transmission are possible but little is known for certain.

Where Is Lyme Disease Found?

Lyme disease has been found on every continent except Antarctica. It is found all across the United States, with a particularly high incidence in the East, Midwest, and West Coast. Rates have increased significantly over time. Some of this increase may be because of disease spread, but it is also likely that it reflects growing public awareness of the disease.

Not all ticks are infected. Within endemic areas, there is considerable variation in tick infection rates depending on the type of habitat, presence of wildlife and other factors. Tick infection rates can vary from 0% to more than 70% in the same area.

“*Lyme disease is most common in children, older adults, and others such as firefighters and park rangers who spend time in outdoor activities and have higher exposure to ticks.*”

This uncertainty about how many ticks are infected makes it hard to predict the risk of Lyme disease in a given region.

In the South, a Lyme-like disease called STARI (Southern Tick-Associated Rash Illness) transmitted by the Lone Star tick has been described. Scientists are still debating about what organism(s) in the Lone Star tick may cause the disease as well as the treatment of patients with a rash in the South. However, Lyme disease has been reported in certain areas of the South and Southeast and patients with STARI may be quite ill. Because of this, patients in the South with a rash should be treated. (Herman-Giddens 2014).

The risk of getting Lyme disease is often reflected in risk maps. Some maps show the number of human cases of Lyme disease reported for surveillance. These maps may not accurately reflect risk because only 10% of reportable Lyme cases are currently captured by CDC surveillance. Other risk maps show the number of infected ticks that researchers have collected in a certain area. These maps are often not accurate because many states and counties have done little or no testing of ticks in the area. The best maps of risk may be [canine maps](#). This is because dogs are routinely screened for Lyme disease through a nationwide program as well as the close association of dogs with humans.



Lyme Disease Symptoms

Symptoms of early Lyme disease may present as a flu-like illness (fever, chills, sweats, muscle aches, fatigue, nausea and joint pain). Some patients have a rash or Bell's palsy (facial drooping). However, although a rash shaped like a bull's-eye is considered characteristic of Lyme disease, many people develop a different kind of Lyme rash or none at all.

Estimates of patients who develop a Lyme rash vary widely, ranging from about 30% to 80%.

For example, a **CDC** report on Lyme carditis, which can be fatal, found that only 42% of cases had a rash.

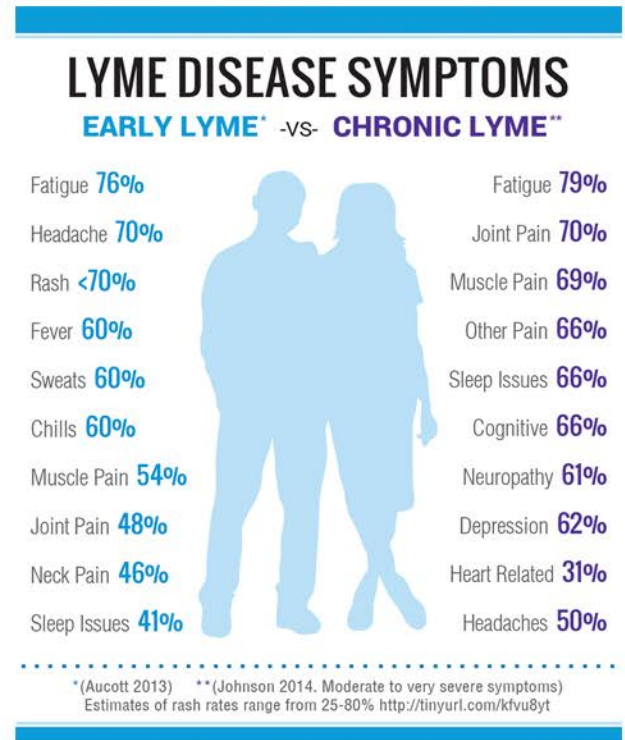
Lyme Disease Symptoms Checklist

LymeDisease.org has developed a [Lyme disease symptom checklist](#) to help you document your exposure to Lyme disease and common symptoms for your healthcare provider. You will receive a report that you can print out and take with you to your next doctor's appointment.

Chronic Lyme Disease Symptoms

If Lyme disease is not diagnosed and treated early, it may become late-stage or chronic. This may also occur when early treatment is inadequate. While some symptoms of chronic or late stage Lyme disease are similar to those of early Lyme, as the graphic below shows, there are important differences.

Lyme disease may spread to any part of the body and affect any body system. Typically, it affects more than one body system. In [our survey](#), which drew over 5,000 responses, patients with chronic Lyme disease reported an average of three severe or very severe symptoms, with 74% reporting at least one symptom as severe or very severe.



An [extensive list of symptoms](#) of chronic Lyme disease was developed by Dr. Joseph Burrascano, a pioneer in treating chronic Lyme disease.

Lyme Disease Symptoms Also Occur In Other Diseases

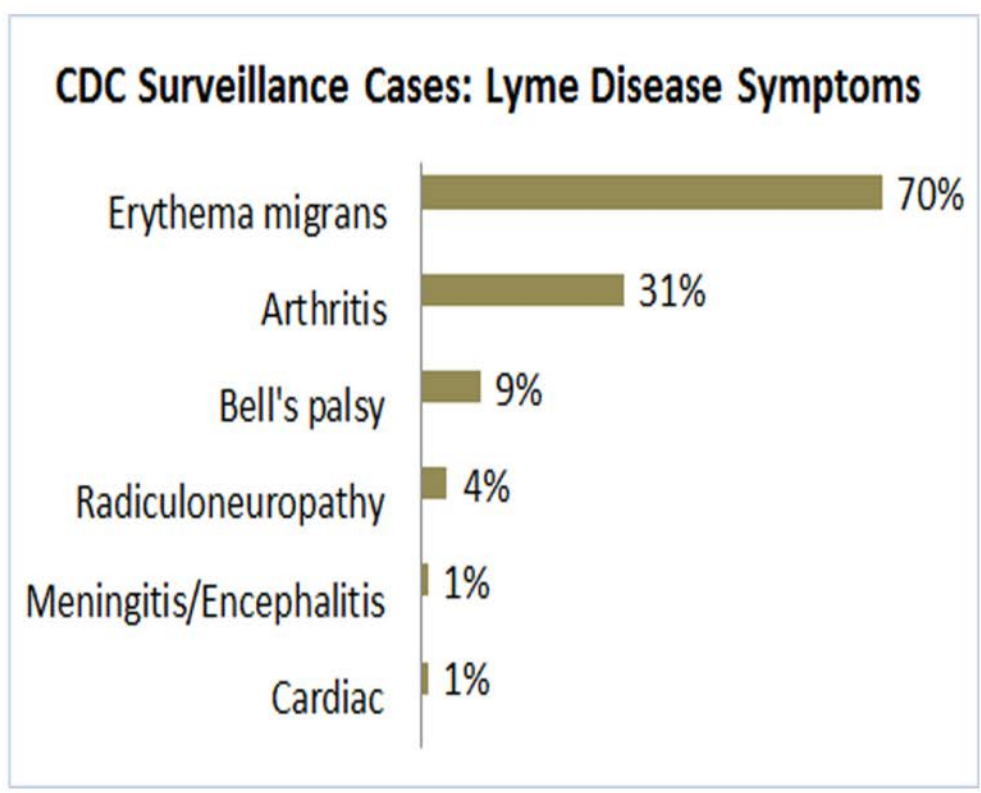
Many Lyme symptoms, such as fatigue, cognitive impairment, joint pain, poor sleep, mood problems, muscle pain, and neurological presentations also occur in other diseases. Hence, the symptoms of Lyme disease significantly overlap those of chronic fatigue, fibromyalgia,

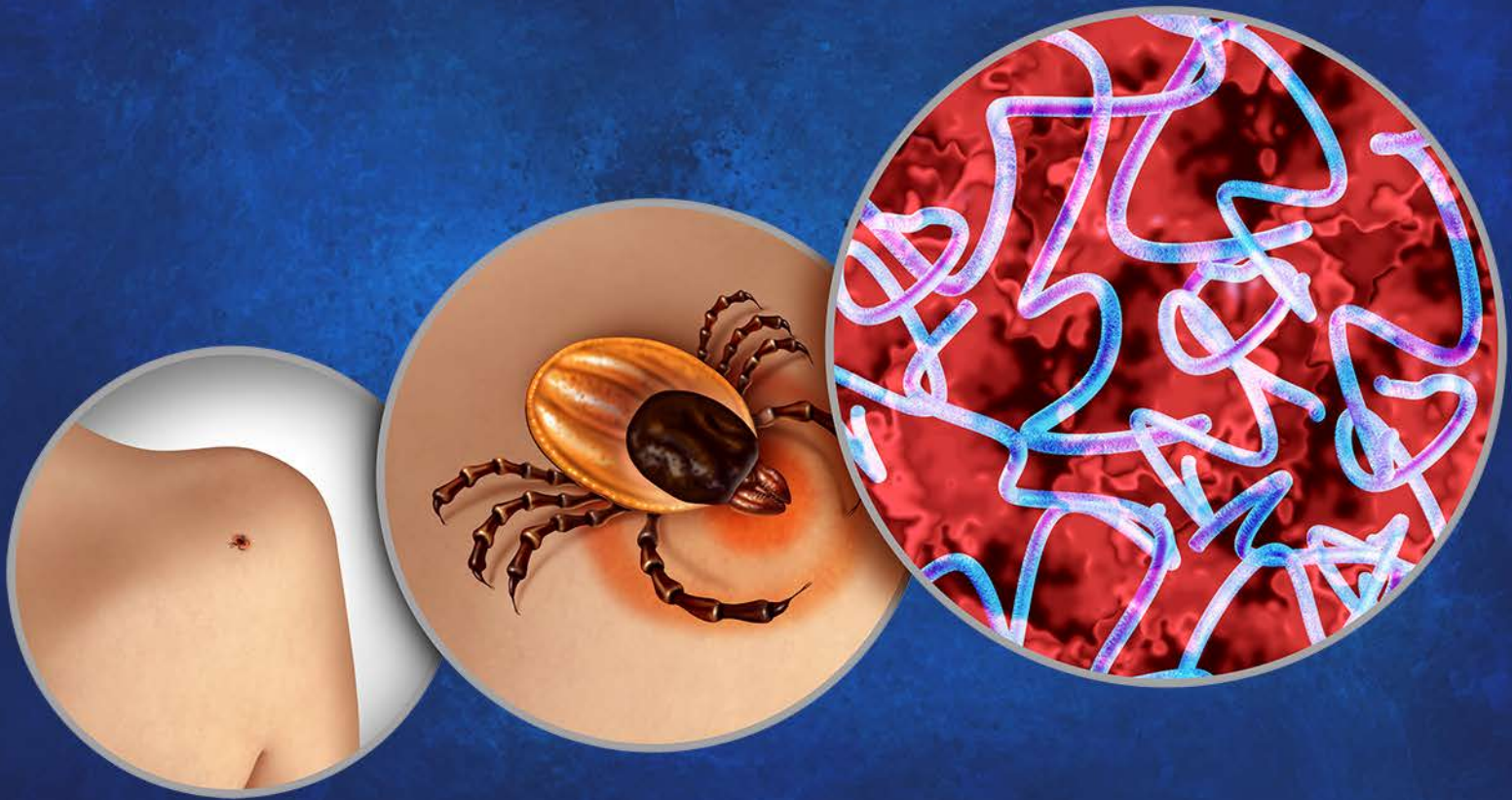
rheumatoid arthritis, multiple sclerosis, Parkinson’s disease, ALS, depression and Alzheimer’s disease.

Many Lyme patients report being misdiagnosed with a different condition before being properly diagnosed with Lyme disease.

Lyme Disease and the CDC

In order for the Centers for Disease Control (CDC) to recognize a Lyme case for surveillance purposes, there must be “objective” findings, such as positive blood tests, Bell’s palsy or joint swelling (even though Lyme blood tests are unreliable and the CDC’s accepted “objective” indicators are not common). The chart below reflects the [CDC-reviewed surveillance case](#) manifestations from 2001 to 2010.





Early Lyme Disease

Early Lyme disease may feel like the flu: fever, sore muscles, headache and fatigue. Some people may develop a highly distinctive rash, which may look like a bull's-eye. However, many people with Lyme never knew they were bitten and never developed a rash.

How Often Does the Lyme Disease Rash Occur?

The CDC reports that rashes occur in 60-80% of cases. However, the true incidence of rash is unknown because no definitive studies on humans have been done. (It wouldn't be ethical to infect people with Lyme just to see if they develop a rash.) In [LymeDisease.org's survey of 3000 patients with chronic Lyme](#), 40% reported a rash. Most of the time the rash is an ordinary red area; however if it is a "bull's-eye" shape with a darker edge, it is a definite sign of Lyme disease and needs immediate treatment.



“Unfortunately this distinctive rash occurs in less than 10% of those who contract Lyme disease. (Smith, 2002) When present, the Lyme rash is more likely to be diffuse.”

What Does the Lyme disease Rash Look Like?

It starts a few days or even several weeks after the bite and then expands over a period of days or weeks to several inches across, perhaps with a central clearing. Untreated, it can last for weeks before fading, or it may fade and recur. The rash may have an irregular shape, blistering or a scabby appearance. Some rashes look like a bruise. Lyme rashes may resemble spider bites, ringworm, or cellulitis. Multiple, so-called "satellite" rashes may appear on different parts of the body.

If you develop a rash, take a photo of it and see a doctor as soon as possible. Other symptoms of early Lyme disease may include a fever, headache, fatigue, or muscle aches.

Unfortunately, diagnostic testing is unreliable in the early stages of infection, often giving false negatives. Treatment should not be delayed pending a positive test result if the suspicion of Lyme disease is high (exposure, tick bite, possible rash).





Chronic Lyme Disease

If Lyme disease is not diagnosed and treated early, the spirochetes can spread and may go into hiding in different parts of the body. Weeks, months or even years later, patients may develop problems with the brain and nervous system, muscles and joints, heart and circulation, digestion, reproductive system, and skin. Symptoms may disappear even without treatment and different symptoms may appear at different times.

Severe Symptoms

Untreated or undertreated Lyme can cause some people to develop severe symptoms that are hard to resolve. This condition may be referred to as post-treatment Lyme disease (PTLD) or chronic Lyme disease (CLD). We don't know exactly how many people who are diagnosed and treated remain ill. CDC estimates range from 10-20%. A recent study of early Lyme disease treated at EM rash reported 36% remain ill. (Aucott 2013).

LymeDisease.org has developed a [Lyme disease symptom checklist](#) to help you document your exposure to Lyme disease and common symptoms for your healthcare provider.

Treatment Guidelines

[International Lyme and Associated Diseases Society \(ILADS\)](#) published treatment guidelines which contains a rigorous assessment of the evidence and found treatment failure rates ranging from 16% to 39% for early treatment. Estimates for patients with chronic Lyme disease are much higher, ranging from 26% to 50%. (Johnson 2004)

Although experts do not often attribute deaths to Lyme disease, studies have documented at least 23. In 2014, the CDC issued a warning regarding [three sudden cardiac deaths](#) related to Lyme carditis.

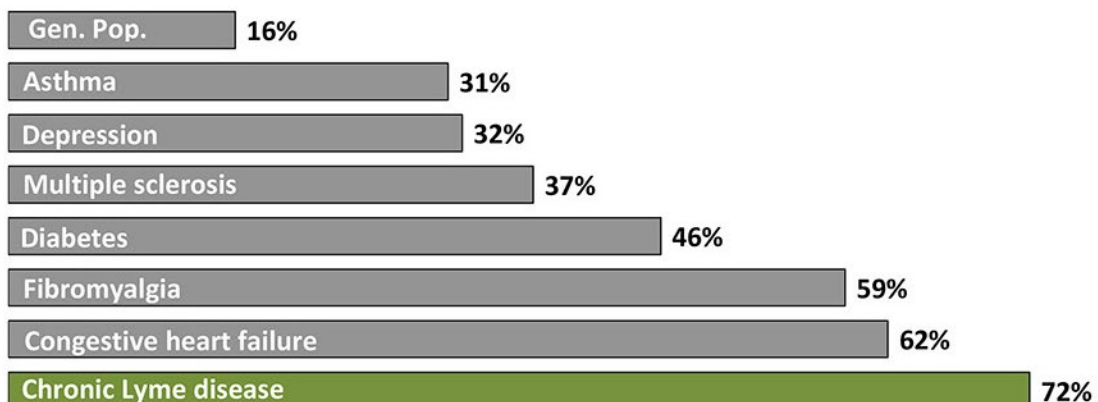
Chronic Lyme Disease Patients Profoundly Debilitated

Many patients with chronic Lyme disease are profoundly debilitated. Investigators of the four NIH-sponsored retreatment trials documented that the patients' quality of life was consistently worse than that of control populations and equivalent to that of patients with congestive heart failure. Pain levels were similar to those of post-surgical patients, and fatigue was on par with that seen in multiple sclerosis.

An [LDo published survey](#) of over 3,000 patients with chronic Lyme disease found that patients suffer a worse quality of life than most other chronic illnesses, including congestive heart failure, diabetes, multiple sclerosis and arthritis. Over 70% of patients with chronic Lyme disease reported fair or poor health. Similar results have been found in other studies. (Cameron, 2008)

Quality of Life

Chronic Lyme patients suffer worse quality of life compared to most other chronic diseases. 72% report their health status as fair or poor.





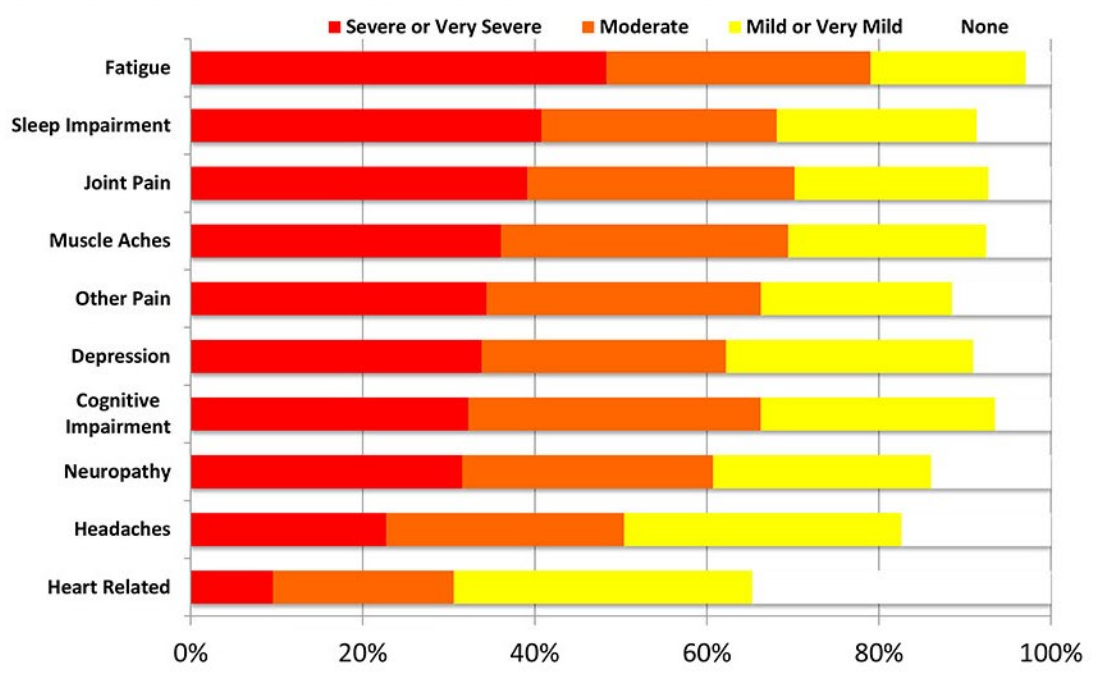
Many of the symptoms associated with Lyme disease are common in other diseases. The CDC surveillance criteria for confirmed cases specifically exclude most of the symptoms that patients report, including fatigue, sleep impairment, joint pain, muscle aches, other pain, depression, cognitive impairment, neuropathy, and headaches. However, these common symptoms can be severe and may seriously affect quality of life.

Chronic Lyme Disease Symptom Severity

In LDo’s chronic Lyme disease survey, over 75% of patients reported at least one symptom as severe or very severe and 63% reported two or more such symptoms. (Johnson 2014) [Find out more about LDo peer-reviewed published surveys.](#) The chart below shows the severity of ten common chronic Lyme symptoms.

Symptom Severity

75% of chronic Lyme patients experience severe or very severe symptoms. 63% describe two or more symptoms as severe or very severe.



The [survey](#) also found that patients with chronic Lyme disease have high disability and unemployment rates. Over 40% of patients with chronic Lyme disease reported that they currently are unable to work because of Lyme disease and 24% report that they have received disability at some point in their illness.



Lyme Disease Diagnosis

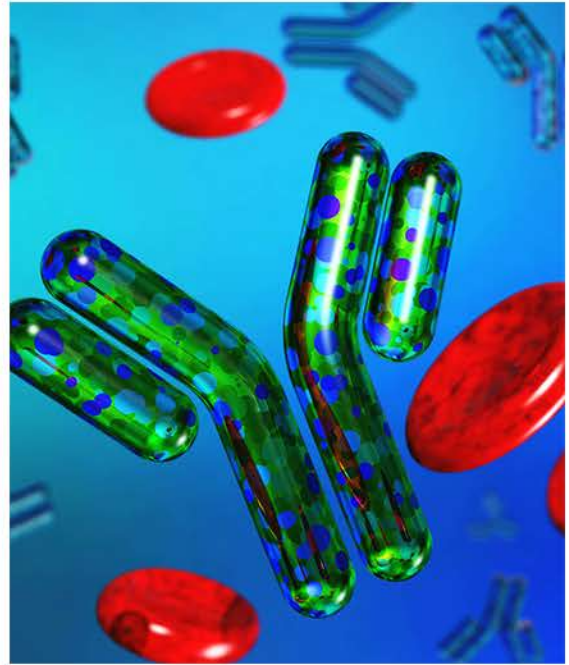
Lyme disease is a clinical diagnosis — based on your medical history, symptoms and exposure to ticks.

Because the typical Lyme disease diagnostic tests are so insensitive, a negative test result does not mean you don't have Lyme. There are many reasons why someone who actually has Lyme may have a negative test result.

There may not have been time for antibodies to develop; the immune system may be suppressed; or the person may be infected with a strain the test doesn't measure.

Lyme disease is known to inhibit the immune system and 20-30% of patients have falsely negative antibody tests.

“56% of patients with Lyme disease test negative using the two-tiered testing system recommended by the CDC.”



Lyme Disease Diagnosis and Testing Highlights

- LMDS consider the specificity of the particular bands that test positive for a patient.
- Although the CDC requires 5 of 10 bands for IgG surveillance purposes, 2 of 5 bands have specificity of 93-96% and a sensitivity of 100%. (Engstrom 1995).
- 56% of patients with Lyme disease test negative using the two-tiered testing system recommended by the CDC. (Stricker 2007)
- The CDC case surveillance definition allows single-tier IgG immunoblot seropositivity using established criteria. (CDC 2011).
- The CDC states: “This surveillance case definition was developed for national reporting of Lyme disease; it is not intended to be used in clinical diagnosis.”
- The College of American Pathologists (CAP) found that ELISA tests do not have adequate sensitivity to be used for screening purposes. (Bakken 1997)
- 52% of patients with chronic disease are negative by ELISA but positive by Western blot. (Donta 2002)

Learn More About Lyme Disease Diagnosis Testing

Tests can not only help to diagnose a disease, but also to manage an illness. A good test can help a doctor assess the severity of disease, estimate the patient's prognosis, monitor the course of disease progression, stability or resolution, detect relapse, and select drugs or adjust therapy. Unfortunately, a test with this capability does not exist for Lyme disease.

LymeDisease.org has developed a [Lyme disease symptom checklist](#) to help you document your exposure to Lyme disease and common symptoms for your healthcare provider. You will receive a report that you can print out and take with you to your next doctor's appointment that may be helpful in your Lyme disease diagnosis.



Lyme Disease Tests

The most common Lyme disease tests are indirect ones. They measure the patient's antibody response to the infection, not the infection itself. The two most-used antibody tests are the enzyme-linked immunosorbent assay (ELISA) and the Western blot.

The CDC recommends that doctors first order an ELISA to screen for Lyme disease and then confirm Lyme disease with a Western blot.

During the first four-to-six weeks of Lyme infection, these Lyme disease tests are unreliable because most people have not yet developed the antibody response that the test measures. Even later in the illness, the two-tiered testing is highly insensitive missing roughly half of those who have Lyme disease.



Lyme Disease Test – Two-tier Testing

Two-tiered Lyme disease testing uses two tests. The first is a screening test that should detect anyone who might have the disease. Tests that do this well have are regarded as having high sensitivity. This test is followed by a second test that is intended to make sure that only people with the disease are diagnosed. Tests that do this well have high specificity.

HIV/AIDS is diagnosed with tests that are both highly sensitive and highly specific. They are accurate more than 99% of the time. In Lyme disease, the second test is highly specific. So there are few false positives. Unfortunately, the screening test is highly insensitive and fails to accurately identify patients who have Lyme disease. The two-tiered test system misses roughly 54% of patients. (Stricker Minerva 2010)

Sensitivity/specificity of commercial two tier testing for convalescent/late stage Lyme disease in the US*			
Study/Year	Patients/Controls	Sensitivity	Specificity
Schmitz (1993)	25/28	66%	100%
Engstrom (1995)	55/159 [†]	55%	96%
Ledue (1996)	41/53	44%	100%
Tilton (1997)	23/23	45%	100%
Trevejo (1999)	74/38	29%	100%
Bacon (2003)	106/559	67%	99%
Binnicker (2008)	35/5	49%	100%
Steere (2008)	76/86 ^{††}	18%	99%
TOTAL	435/951	46%	99%

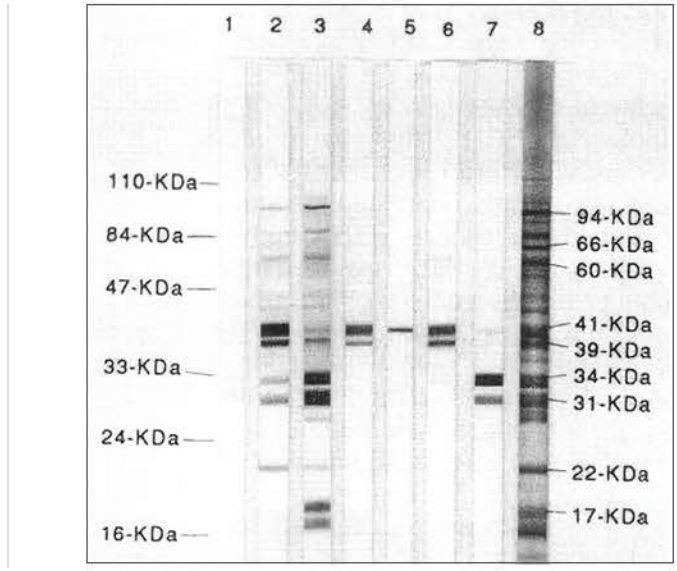
* Limited to studies from the US that included negative controls;
[†]Non-commercial ELISA and Western blot; ^{††}Non-commercial ELISA

Because of this, LDo recommends the patients and physicians skip the ELISA and go straight to the Western blot.



Lyme Disease Test – Two-tier Testing

Labs performing a Western blot use electricity to separate proteins called antigens into bands. The read-out from the Western blot looks like a bar code. The lab compares the pattern produced by running the test with your blood to a template pattern representing known cases of Lyme disease. If your blot has bands in the right places, and the right number of bands, it is positive.



The CDC requires 5 out of 10 bands for a positive test result. However, because some bands on the Western blot are more significant than others your doctor may decide you have Lyme disease even if your Western blot does not have the number of bands or specific bands recommended by the CDC. Different laboratories use different methods and criteria for interpreting the test, so you can have a positive test result from one lab and a negative test result from another.

For a comprehensive explanation of the western blot test, download [Understanding Western Blot Lyme disease test](#).

The chart below will help you understand how to interpret the western blot test.

Interpretation of the Western blot—More is not necessarily better.

Band kDa	Band importance	IgG		IgM	
		Ma et al. 2 of 6	CDC 5 of 10	Ma et al 2 of 5	CDC 2 of 3
18	Thought to be specific				
22	Thought to be specific				
23-25	OSP-C highly specific				
28	Not specific				
30	Thought to be specific				
31	OSP-A highly specific				
34	OSP-B highly specific				
37	Thought to be specific				
39	Thought to be specific				
41	Non-specific flagella				
45	Non-specific				
58	Non-specific				
66	Non-specific				
73	Non-specific				
88	Thought to be specific				
93	Thought to be specific				

Engstrom found 2 of 5 bands to be highly sensitive and specific for Lyme disease (Engstrom 1995), while 46 of 66 symptomatic pediatric patients with a history of bulls eye rash and tick bite were negative by CDC criteria (Fawcett 1995 Rheumatology Symposia Abstract #1254.) The CDC criteria are intended only for surveillance purposes, not diagnosis. Many physicians interpret the Western blot based on the number and specificity of the patient’s bands. See also (Ma et al. 1989).

Lyme ImmunoBlots Test

The IgM and IgG ImmunoBlot (IB) are qualitative immunoassays in which antibodies are visualized. They are used to determine whether pathogen-specific antibodies are present in patient serum or plasma. These tests are generally more sensitive and specific than the Western Blot, ELISA and IFA tests. Learn more about these Lyme disease tests that [IGENEX offers](#).

Other Lyme Disease Tests

Three other tests that may be used to diagnose Lyme disease are polymerase chain reaction (PCR), antigen detection and culture testing. They are called “direct” tests because they detect the bacteria, not just your immune response to it.

PCR multiplies a key portion of DNA from the Lyme bacteria so that it can be detected. While PCR is highly accurate when the Lyme DNA is detected, it produces many false negatives. This is because the Lyme bacteria are sparse and may not be in the sample tested.

Antigen detection tests look for a unique Lyme protein in fluid (e.g. blood, urine, joint fluid). Sometimes people whose indirect tests are negative are positive on this test.

Culture is the “gold standard” test for identifying bacteria. The lab takes a sample of blood or other fluid from the patient and attempts to grow Lyme spirochetes in a special medium.

“ *The IgM and IgG ImmunoBlot (IB) are generally more sensitive and specific than the Western Blot, ELISA and IFA tests.* ”

Although culture tests are generally accepted as proof of infection, the CDC has advised caution on the only commercially available culture test developed by Advanced Laboratory Services. LDo recognizes that the test is new and requires further validation in other studies. However, we believe that informed patients should be able to choose the test if they prefer. Choice is particularly important given the low quality of Lyme disease tests generally.





Recommended Labs

Although the CDC recommends that patients use “FDA-approved” tests, LDo does not support this restriction because there are no FDA-approved test for Lyme disease. Instead, the the FDA has “cleared” certain lab tests, but these test are not required to demonstrate that they are effective or safe, they are only required to be “equivalent” to test previously cleared. The current FDA cleared tests have poor sensitivity and miss more than 50% of patients with Lyme disease. The US Centers for Medicare & Medicaid Services (CMS) requires tests without FDA approval to undergo a rigorous certification process. CMS regulates all laboratory testing (except research) performed on humans in the U.S. through the Clinical Laboratory Improvement Amendments (CLIA). CLIA certification is designed to ensure quality laboratory testing.

All clinical laboratories must be properly certified to receive Medicare or Medicaid payments. CLIA covers approximately 244,000 laboratory entities.

Two highly specific bands (OspA and OspB) are not included in the CDC bands because they were used for vaccine development. Your doctor may want to know if you have antibodies directed towards those proteins. A few labs test for them.

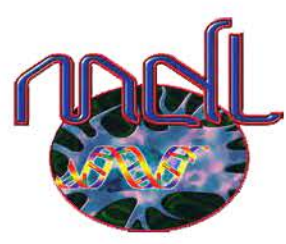
LDo recommends that you use a CLIA-approved lab that specializes in testing for tick-borne diseases and reports all bands on the Western blot. The healthcare professional ordering the test must ask the lab to report all bands except in the case of IGeneX, which automatically reports all bands. Blots may still vary in sensitivity.



IGeneX
800-832-3200



StonyBrook
631-444-3824



MDL
877-269-0090



Lyme Disease Treatment

There is significant controversy in science, medicine, and public policy regarding Lyme disease. Two medical societies hold widely divergent views on the best approach to diagnosing and treating Lyme disease. The conflict makes it difficult for patients to be properly diagnosed and receive treatment.

Two Standards Of Care For Lyme Disease Treatment

One medical society, the Infectious Diseases Society of America (IDSA), regards Lyme disease as “hard to catch and easy to cure” with a short course of antibiotics. IDSA claims that spirochetal infection cannot persist in the body after a short course of antibiotics. The group also denies the existence of chronic Lyme disease.

In contrast, the International Lyme and Associated Diseases Society (ILADS), regards Lyme disease as often difficult to diagnose and treat, resulting in persistent infection in many patients. ILADS recommends individualized treatment based on the severity of symptoms, the presence of tick-borne coinfections and patient response to treatment.

LDo believes that patients and their doctors should make Lyme disease treatment decisions together. This requires that patients be given sufficient information about the risks and benefits of different treatment options. Then, patient and health care provider can collaborate to reach an informed decision, based on the patient’s circumstances, beliefs and preferences.

LDo endorses the [ILADS guidelines](#), which allow greater exercise of clinical discretion by physicians and provide patients with more treatment options. It is the doctor’s responsibility to tell patients about the different treatment options so that patients can make an informed choice.

“*LymeDisease.org believes that patients and their doctors should make Lyme disease treatment decisions together. This requires that patients be given sufficient information about the risks and benefits of different treatment options.*”

Early Lyme Disease Treatment

ILADS doctors are likely to recommend more aggressive and longer antibiotic treatment for patients. They may, for instance, treat “high risk” tick bites where the tick came from an endemic area, was attached a long time, and was removed improperly. They may treat a Lyme rash for a longer period of time than the IDSA recommends, to ensure that the disease does not progress. They are unlikely to withhold treatment pending laboratory test results.

Late Or Chronic Lyme Disease Treatment

Experts agree that the earlier you are treated the better, since early treatment is often successful. Unfortunately, a substantial portion of patients treated with short-term antibiotics continue to have significant symptoms. The quality of life of patients with chronic Lyme disease is similar to that of patients with congestive heart failure. Doctors don’t agree about the cause of these ongoing symptoms. The primary cause of this debate is flawed diagnostic testing.

Late Or Chronic Lyme Disease Treatment

There is currently no test that can determine whether a patient has active infection or whether the infection has been eradicated by treatment.

The IDSA thinks Lyme disease symptoms after treatment represent a possibly autoimmune, “post-Lyme syndrome” that is not responsive to antibiotics. The IDSA essentially regards Lyme disease as an acute infection like strep throat that can be treated with a short course of antibiotics. The IDSA guidelines are now eight years old and do not reflect recent science.

ILADS physicians believe that ongoing symptoms probably reflect active infection, which should be treated until the symptoms have resolved. These physicians use treatment approaches employed for persistent infections like tuberculosis, including a combination of drugs and longer treatment durations. The ILADS guidelines have just recently been updated using a rigorous review of the medical literature.

The ideal antibiotics, route of administration and duration of treatment for persistent Lyme disease are not established. No single antibiotic or combination of antibiotics appears to be capable of completely eradicating the infection, and treatment failures or relapses are reported with all current regimens, although they are less common with early aggressive treatment.



All medical treatments have risks associated with them. While the safety profile of antibiotics is generally quite good, only the patient (in consultation with his or her physician) can determine whether the risks outweigh the potential benefits of any medical treatment.

An ILADS doctor may consider the possibility of tick-borne coinfections, particularly if a patient does not respond to treatment or relapses when treatment is terminated. Other factors to consider are immune dysfunction caused by Lyme; silent, opportunistic infections enabled by the immune dysfunction; hormonal imbalance caused by Lyme; and other complications.

Considerations While On Lyme Treatment

Antibiotics can wipe out beneficial intestinal flora, leading to a wide variety of additional health problems. It is important to take probiotics while on antibiotics to maintain a healthy balance of gut bacteria. Furthermore, antibiotics may interact with other drugs, supplements or food. The National Institutes of Health’s MedLinePlus website gives information about drug interactions.



Children with Lyme disease

Children with Lyme disease have special issues. Since they can't always explain what feels wrong, they may just come across as cranky and irritable. They suffer when their bodies hurt, when their illness disrupts their sleep at night, when they struggle in school, when they don't even feel like playing.

Children may feel confused, lost and betrayed by parents and teachers who fail to recognize that they are sick and need help.

Mothers and fathers may not understand what the child’s normal baseline is. Is this the “terrible twos” or “the nine-year-old change” or is something really wrong?

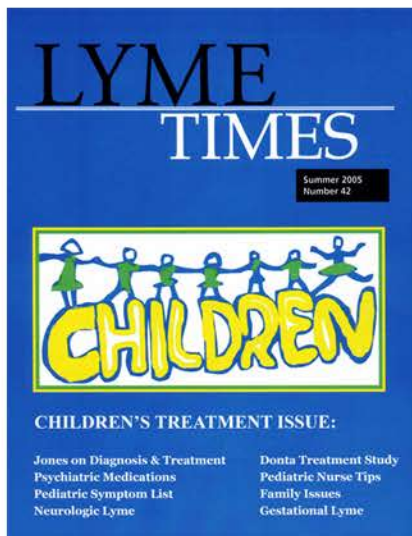
Because the symptoms of Lyme disease can be non-specific, vague and changeable, adults may not even realize these children are ill. They may suspect them of making things up to gain attention or to avoid school. Children with Lyme often have trouble in the classroom, because the disease can contribute to learning disabilities and behavioral problems.



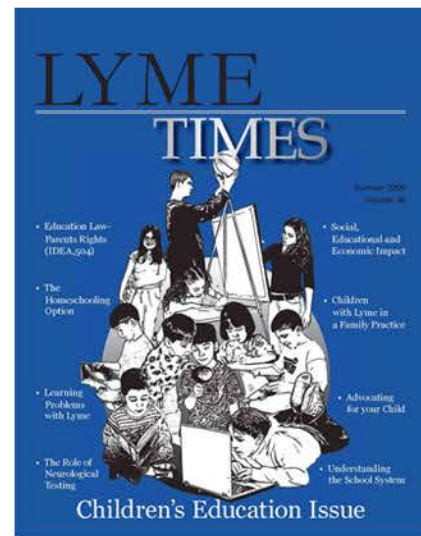
Children are especially vulnerable to tick-borne diseases because they are physically low to the ground, where the ticks are. They play in leaves, roll on grass, cuddle with pets and otherwise increase their exposure to ticks.

The Lyme Times - Childrens’ Issues

LymeDisease.org is the publisher of The Lyme Times, a quarterly online magazine available to members. We have two issues that have a wealth of information about children and Lyme disease. Please click on the buttons below to view the Table of Contents of each issue.



[VIEW CHILDREN’S TREATMENT ISSUE](#)



[VIEW CHILDREN’S EDUCATION ISSUE](#)

Check Your Child's Symptoms

LymeDisease.org has developed a Lyme disease symptom checklist to help you document your and your children's exposure to Lyme disease and common symptoms for your healthcare provider. You will receive a report that you can print out and take with you to your next doctor's appointment. Learning disabilities and behavioral problems.



SCAN THE QR CODE TO CHECK YOUR CHILD'S SYMPTOMS



DOES YOUR CHILD HAVE LYME DISEASE?

Children account for 25% of Lyme disease cases.

CHECK YOUR SYMPTOMS

Lyme pediatric specialist Charles Ray Jones, MD, compiled a list of common symptoms of infection in his young patients:

- severe fatigue unrelieved by rest
- insomnia
- headaches
- nausea, abdominal pain
- impaired concentration
- poor short-term memory
- inability to sustain attention
- difficulty thinking & expressing thoughts
- difficulty reading and writing
- being overwhelmed by schoolwork
- difficulty making decisions
- confusion
- uncharacteristic behavior
- outbursts and mood swings
- fevers/chills
- joint pain
- dizziness
- noise and light sensitivity

Among Jones' patients, only half have had a known tick attachment. Fewer than 10% have had an erythema migrans rash (bull's-eye).

Dr. Jones has also documented congenital, or gestational, Lyme disease in some children he thinks were infected in utero or by breastfeeding. In these patients his suspicion is raised when the child has:

- frequent fevers
- increased incidence of ear and throat infections
- increased incidence of pneumonia
- irritability
- joint and body pain
- poor muscle tone
- gastroesophageal reflux
- small windpipe (tracheomalacia)
- cataracts and other eye problems
- developmental delay
- learning disabilities
- psychiatric manifestations

If you believe your child may have Lyme or other tick-borne diseases, we highly recommend that he or she be evaluated by an ILADS-affiliated health care provider.

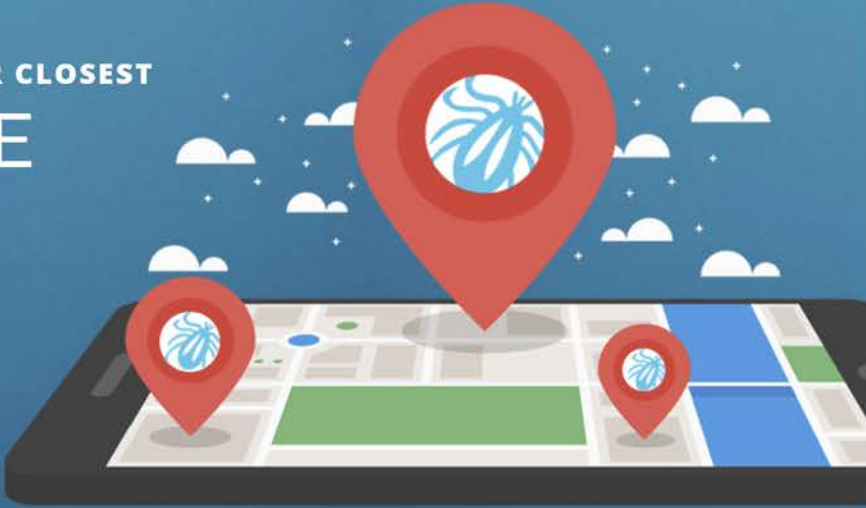
For the past 25 years, LymeDisease.org has been connecting patients with Lyme-literate practitioners who specialize in caring for patients with Lyme disease. Click below to go to our online physician directory.

Lyme Disease Physician Referral

**CONNECTING YOU WITH YOUR CLOSEST
LYME DISEASE
SPECIALIST**

For the past 25 years, LymeDisease.org has been connecting patients with Lyme-literate doctors who specialize in caring for patients with Lyme disease.

[FIND A LYME DOCTOR](#)





Resources

DOWNLOADS FROM LYME SPECIALISTS:

Dr. Charles Ray Jones is the world’s foremost expert on pediatric tick-borne diseases, having treated more than 12,000 children. [Click here](#) for his paper, *Rationale on Long Term Antibiotic Therapy in Treating Lyme Disease*

Dorothy Pietrucha, MD, a pediatric neurologist, presents an overview of diagnosis and treatment with case histories in *Neurological Manifestations of Lyme Disease in Children*.

Ann Corson, MD, board-certified family practitioner, has a full time Lyme and tick-borne disease practice in Chester County, PA, with a special interest in children and pregnant women. View her slideshows on: *Pediatric Lyme disease, neuropsychiatric presentations of Lyme disease,*

Psychotherapist **Sandy Berenbaum, LCSW, BCD**, has devoted much of her career to children and adolescents with Lyme disease. [Click here](#) to read her story *Kids and Lyme Disease – How It Affects Their Learning*.

Pennsylvania psychiatrist **Virgina Sherr, MD**, has treated many children with Lyme disease. Read her poignant story of two different young people with Lyme disease who ended up in jail: *The Pillaging of Personalities: Our Lost Kids are Being Highjacked by Spirochetes*.

[Gestational Lyme Disease Case Studies of 102 Live Births](#)

[Gestational Lyme Disease Bibliography](#)

[“Healthy Mom Best Prescription for Healthy Baby”](#)

Useful Links:

[Children’s Lyme Disease Network](#)

[LymeParents Online Support Group](#)

[Dr. Jones’ Kids](#)

[LymeLight Foundation](#)

[LymeAid4Kids](#)

[Book: When Your Child Has Lyme Disease: A Parent’s Survival Guide](#)

[Lyme Times: Children’s Education Issue](#)

[Lyme Times: Children’s Treatment Issue](#)



Pets and Lyme disease

People who own pets should be particularly concerned about ticks, both for their animals' sake and for their own. Dogs, cats and horses may contract Lyme disease and other bacteria carried by ticks, including bartonella, babesia, ehrlichia, anaplasma, Rocky Mountain spotted fever and tick paralysis. Symptoms in pets may include joint problems, limping, or lethargy.

Ticks on your pets can be a danger to you. Animal fur can act like a “tick magnet.” You may be exposed to ticks when you snuggle with your cat or dog, or when you ride your horse. Pet owners should check their pets for ticks and use tick collars or other topical flea and tick treatments.

Dogs provide a good indication of a likely exposure of their owners to infected ticks as they may visit the same outdoor areas. Rates of infection in dogs are regarded as “sentinels” of human infection and may be used to monitor infection rates. The CDC acknowledges that the more dogs with Lyme disease, the higher the frequency in humans.

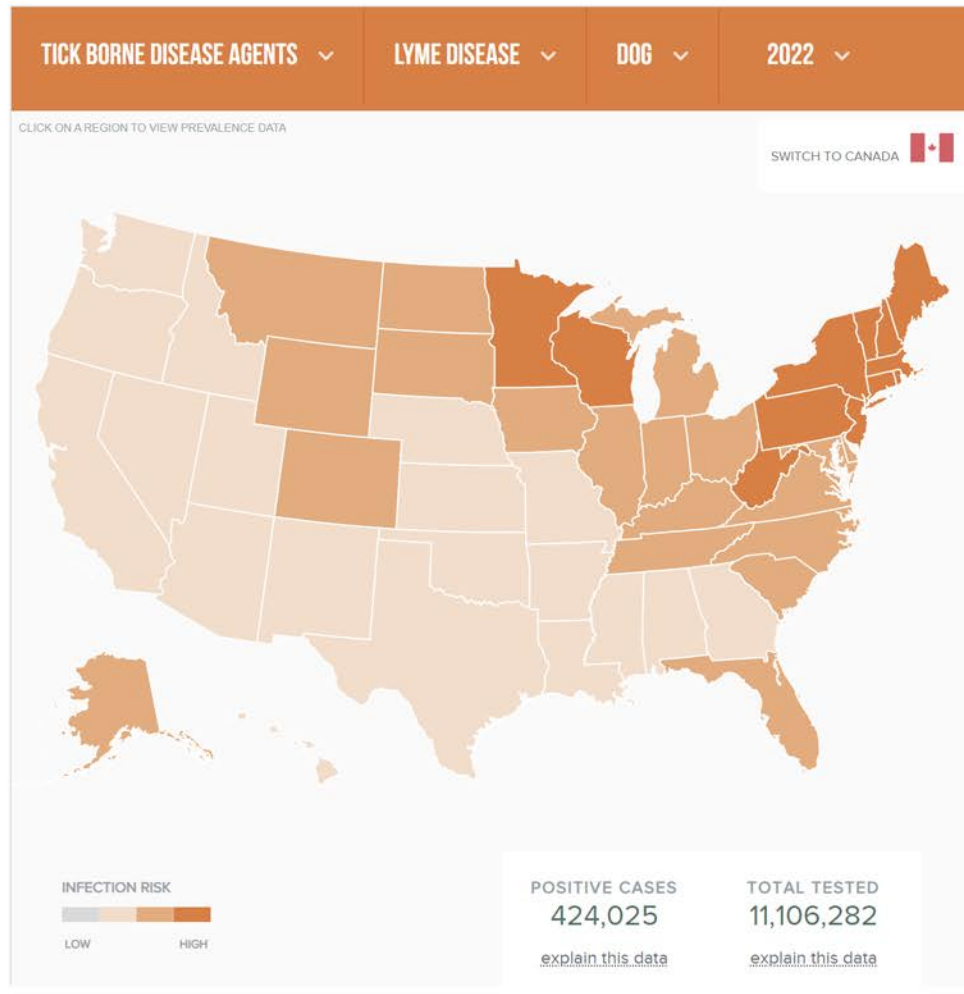


People who own pets should be particularly concerned about ticks, both for their animals’ sake and for their own.

Because of the widespread screening of dogs throughout the United States, [canine sentinel maps](#) may be better indicators, of not only canine risk, but also human risk than either tick flagging studies or CDC surveillance:

In addition, canine maps also show rates of anaplasma and ehrlichia.

Animals are generally not viewed as a direct source of Lyme or coinfections. However, cats may directly infect humans with bartonella through scratching or biting. Studies in some parts of the United States show that up to 80% of stray cats are infected with bartonella.





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About Ticks and Lyme Disease

Ticks are small crawling bugs in the spider family. They are arachnids, not insects. There are hundreds of different kinds of ticks in the world. Many of them carry bacteria, viruses or other pathogens that cause disease in humans and/or animals.

In the midwestern and eastern United States, *Ixodes scapularis* or deer tick is the primary vector of Lyme disease. On the West Coast, the spirochete is carried by *Ixodes pacificus* or western black-legged tick. In the South, lone star ticks (*Amblyomma americanum*) can also transmit Lyme disease or a closely related illness.

Ticks have four life stages: egg, larva, nymph and adult. In each stage after hatching, they suck blood from animals like mice, squirrels, birds and deer. Then they drop off, enter a dormant period and molt to enter the next stage.



Photo courtesy: California Department of Public Health

LIFE CYCLE OF TICKS



Ticks don't start out being infected with Lyme. They get it by feeding on an infected animal, often a mouse or other small rodent. Then, they pass it along to the next animal or person they bite.

How long does it take the tick to transmit Lyme?

Experts disagree about how long it takes a tick to transmit Lyme disease. The CDC says that in most cases, the tick must be attached more than 24 hours.

We think that gives people a false sense of security. In some research studies, 5-7% of nymphs transmitted the Lyme

bacteria in less than 24 hours. One paper reported on a case of Lyme disease transmitted after six hours of tick attachment. The risk may be low the first day, but it's not zero.

Furthermore, some studies show that only 30% of patients with Lyme disease recall a tick bite. If people don't even realize that they were bitten, how could they know how long the tick was attached?

The longer a tick stays on you, the more likely it will transmit disease. It's important to find and remove any tick as soon as possible.

Can other bugs give me Lyme?

Researchers have found spirochetes in mosquitoes and other blood-sucking insects. But it has not been proven that they can transmit the infection.

A tick is uniquely suited to carry and spread Lyme disease. Spirochetes have co-evolved with ticks over millions of years. Tick saliva contains immune suppressors that help disseminate the bacteria throughout the host's body. And, because ticks feed on many different animals, they can spread the disease widely.

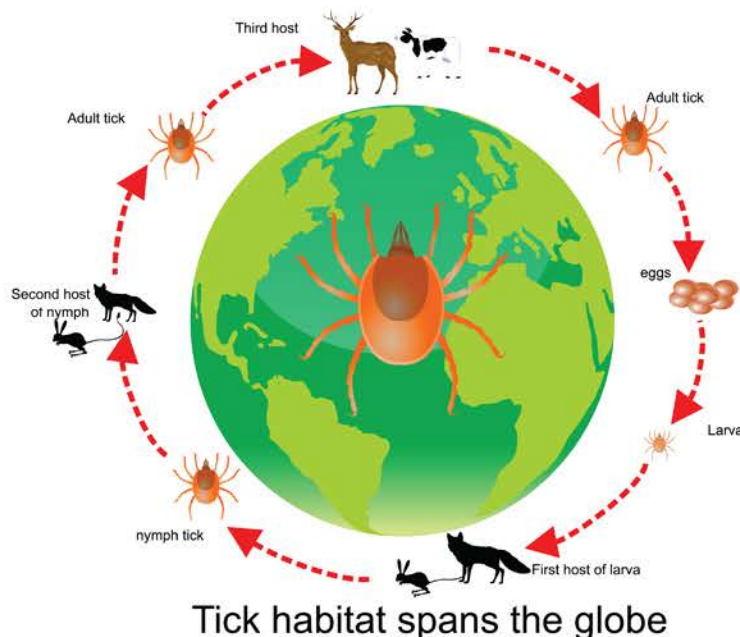
Where do we find ticks?

Generally, you can find ticks where the animals they feed on live. This usually includes wooded and grassy areas. An adult tick “quests” for its next blood meal by climbing up grasses and bushes to wait for an animal to pass by. Nymphs and larvae are typically found in layers of decomposing leaves underneath trees. Ticks thrive in damp environments and are less active in hot, dry weather.

Which ticks should I worry about?

Nymphal ticks cause most cases of Lyme disease. Because nymphs are as small as poppy seeds and their bite is painless, people often don't realize they have been bitten. Adult ticks can also infect humans, but are easier to spot and remove.

Not all ticks are infected. Because tick studies have only been done in a relatively few places, in most of the US, tick infection rates are unknown. Even in places



where ticks generally do not carry Lyme, there may be hotspots of infection depending on local conditions. The tick infection rate may also change from year to year, even in one location.

To get a better idea of which tick-borne diseases have been found in your area, [check this site](#).

Animal Hosts

Adult ticks feed and mate primarily on deer. You may also find adult ticks on dogs, horses and other domesticated animals. Nymphs feed primarily on smaller animals. These include squirrels, mice, lizards, rabbits, and birds that feed on the ground. Migratory birds help distribute ticks throughout the country.

Know Your Ticks

A multitude of environmental and human factors has created a near “perfect storm” over the past 20 years leading to a population explosion of ticks throughout North America. [Learn more about the types of ticks](#).



Types of Ticks

A multitude of environmental and human factors has created a near “perfect storm” over the past 20 years leading to a population explosion of ticks throughout North America. There are two families of ticks found in the United States: Ixodidae (hard ticks) and Argasidae (soft ticks).

Of the 700 species of hard ticks and 200 species of soft ticks found throughout the world, only a few are known to bite and transmit disease to humans.

Hard ticks and soft ticks have different life cycles, growing larger and changing their appearance at each stage.

Hard Ticks (Ixodidae)

Hard ticks (Ixodidae) begin as an egg that is laid by an adult female tick. Once the egg hatches a larva emerges that must then find and feed on a small mammal or bird (host). After feeding it drops to the ground from the host and goes through a molting process, emerging as a nymph.

Nymphal hard ticks then seek larger hosts, and after feeding drop off and molt into adults. The life cycle of hard ticks lasts one to two years depending on the species. The bite of a hard tick is generally painless, with a feeding process lasting several hours, to days, even weeks.

Soft Ticks (Argasidae)

Soft ticks (Argasidae), like hard ticks begin as an egg, hatch into a larva, feed and then molt into a nymph. Nymphal soft ticks may go through as many as seven phases as nymphs, requiring a blood meal at each stage.

Soft ticks' life cycle lasts from months to years depending on the species. The bite is typically painless and only lasts 15-30 minutes, making it harder to detect.

While both hard and soft adult ticks are easiest to identify, it is important to note that nymphal ticks are equally capable of

transmitting disease. In some areas the nymphal tick infection rate is actually higher than the adult tick infection rate.

The following is a list of ticks found in the United States that are known to bite and transmit disease to humans

KNOW THE TYPES OF TICKS

American Dog Tick (*Dermacentor Variabilis*)



The American dog tick has a dark brown body.

Females have an off-white shield, while adult males

look more mottled. The greatest risk of being bitten is from the adult females during the spring and summer months.

Pathogens: This species is the primary vector of the bacteria that cause Rocky Mountain spotted fever ((*Rickettsia rickettsii*)). It is also known to transmit Tularemia (*Francisella tularensis*), Ehrlichia, Anaplasma, and tick paralysis.

Location: This tick has a broad distribution east of the Rocky Mountains, throughout the East and Gulf Coast, along the Pacific Coast, into Canada and parts of Alaska. American dog ticks are mostly found in areas with little or no tree cover, such as tall grassy fields and low lying brush and twigs, as well as along walkways and trails.

Blacklegged “Deer” Tick (*Ixodes Scapularis*)



This tick is most easily identified by its reddish-orange body, black shield and dark black legs.

Pathogens: The deer tick is known to transmit *Borrelia burgdorferi* (the agent of Lyme disease), *Borrelia mayonii* (which causes a Lyme-like illness), *Borrelia miyamotoi* and *Borrelia hermsii* (that both cause relapsing fever Borreliosis), *Ehrlichia muris* (ehrlichiosis), *Anaplasma phagocytophilum microti* (babesiosis), multiple species of *Rickettsia*, deer tick virus, and Powassan virus. This tick is also suspected of transmitting *Bartonella* to humans.

Location: Over the last two decades, the distribution of blacklegged ticks has expanded. They are now found throughout the eastern U.S., large areas in the north and central U.S., and the South. The northern distributions of the blacklegged tick are continuing to spread in all directions from two major endemic areas in the Northeast and Upper Midwest. It’s important to note that adult ticks will search for a host any time when temperatures are above freezing, including winter. brush and twigs, as well as along walkways and trails.

Blacklegged ticks are found in a wide variety of habitat that are suitable for birds, large and small mammals such as mice, deer, squirrel, coyotes and livestock. All life stages can bite humans, but nymphs and adult females are most commonly found on people who are in contact with grass, brush, leaves, logs or pets that have been roaming the outdoors.

Brown Dog Tick (*Rhipicephalus Sanguineus*)



The brown dog tick is a reddish brown with a narrow shape in comparison to other ticks.

Pathogens: All life stages of this tick can transmit Rocky Mountain spotted fever (*Rickettsia rickettsia*), Q Fever, and other rickettsioses to humans. They can also transmit several diseases specific to dogs.

Location: Dogs are the primary host for the brown dog tick which is found world-wide. The brown dog tick can survive and breed in nature but live primarily in and around homes with dogs (for example, dog beds and kennels). These ticks are capable of spending their entire life cycle indoors.

To eradicate brown dog tick infestations, experts recommend: treating all pets the house and yard, sanitize the pet beds and other areas the dog frequents, including the car. This process may take repeated applications over several months.

Groundhog Tick (*Ixodes Cookei*)



The groundhog tick, also known as woodchuck tick, has a light brown or blond color.

Pathogens: The groundhog tick is the primary vector for Powassan virus disease.

Location: This tick is found throughout the eastern half of the United States. All life stages of this tick feed on a variety of warm-blooded animals, including groundhogs, skunks, squirrels, raccoons, foxes, weasels, and occasionally humans and domestic animals.

Lone Star Tick (*Amblyomma Americanum*)



This tick is reddish-brown in color. The adult female is distinguished by a white dot or “lone star” on her back.

Pathogens: The nymphal and adult ticks can transmit human *monocytotropic ehrlichiosis* (HME), Ehrlichiosis (*Ehrlichia chaffeensis*, *Ehrlichia ewingii*, and *Panola Mountain ehrlichia*), *Rickettsiosis*, Rocky Mountain spotted fever (RMSF), Tularemia (*Francisella tularensis*), Heartland virus, Bourbon virus, Q fever and tick paralysis, as well as *Borrelia lonestari*, which causes Southern tick-associated rash illness “STARI,” an illness almost identical to Lyme.

Location: The lone star tick is widely distributed throughout the Eastern U.S. but is most prevalent in the South. These ticks are notoriously aggressive biters, with the greatest risk of being bitten from early Spring through late Fall.

Lone Star Tick (continued) (*Amblyomma Americanum*)

Note: The bite of this tick has been associated with delayed allergic reactions to the consumption of red meat in some humans. This condition, known as “alpha-gal” allergy, is increasingly being recognized as a health problem throughout this tick’s geographic range.

Pacific Coast Tick (*Dermacentor Occidentalis*)



The Pacific Coast tick has a mottled brownish-black color.

Pathogens: All life stages of this tick can transmit Rocky Mountain spotted fever to humans and their pets. It can also transmit Colorado tick fever virus (CTFV), Pacific Coast tick fever (spotted fever *Rickettsia* 364D), the *Rickettsia* of Q fever and *Rickettsia philippi* (a spotted fever rickettsiosis), as well as the bacterium that causes Tularemia. The bite of this tick causes a wound that is commonly mistaken for other biting insects and spiders.

Location: The Pacific coast tick is prevalent in the Southwestern U.S. It has a broad range from Baja Mexico into Oregon. The Pacific Coast ticks are the most common tick found throughout California.

Rocky Mountain Wood Tick (*Dermacentor Andersoni*)



These ticks are reddish-brown and look very similar to American dog ticks. The adult males have a cream-colored shield.

Pathogens: This tick is the primary vector of the Colorado tick fever virus (CTFV), as well as the agents of Rocky Mountain spotted fever (*Rickettsia rickettsii*), Q fever and tularemia. The saliva of the Rocky Mountain wood tick contains a neurotoxin that can occasionally cause tick paralysis in humans and pets. The toxin takes anywhere from 24-72 hours to dissipate after tick removal.

Location: Rocky Mountain wood ticks are found primarily in scrublands, lightly wooded areas, open grasslands, and along trails. They occupy the area between the eastern and western distribution of the American dog tick and extend into Canada. In the U.S., their geographical distribution is generally restricted to higher elevations above 4,000 feet.

These ticks can be active from January through November, but their activity diminishes during the hot and dry mid-summer period. Adult wood ticks can be found questing about knee-high on the tips of vegetation. They prefer to feed on medium to large mammals, but can survive up to 600 days without feeding.

Soft Ticks (*Ornithodoros*)



Soft ticks do not have a hard shell and are shaped like a large raisin.

Pathogens: This tick is the primary vector of two principal North American agents of tick-borne

(TBRF) known as *Borrelia hermsii* and *Borrelia turicatae*.

Location: Soft ticks are distributed widely throughout the western United States, including Texas, and are roughly limited to coniferous forests at elevations between 900 – 2,000 meters above sea level. People usually are bitten as they sleep in rustic mountain cabins that have been previously infested with rodents.

In Texas, TBRF may be associated with the exploration of caves. Because the bite is painless victims are often unaware they have been bitten. Documented outbreaks of TBRF have occurred at national parks and vacation cabins in Colorado, Arizona, and the Lake Tahoe area in California.

Western Blacklegged Tick (*Ixodes Pacificus*)



These ticks have a reddish body with a black shield and black legs.

Pathogens: This tick transmits Lyme disease,

Borrelia miyamotoi disease (a relapsing fever Borreliosis), babesiosis, ehrlichiosis, and human granulocytic anaplasmosis (HGA). It also is suspected of transmitting *Bartonella* to humans. Although all life stages of this tick can bite, nymphs and adult females are thought to be the primary cause of illness in humans.

Location: While the western blacklegged tick is most prevalent in California, being established in 55 out of 58 counties, it can also be found in five other western states: Oregon, Washington, Arizona, Nevada and Utah.

Studies indicate the geographic distribution of the western blacklegged tick has not expanded over the past two decades, although active surveillance efforts for this tick outside California have been very limited. The tick can be found along deer trails in grassy coastal regions, dense woodlands, amongst fallen leaves or fir needles, and on fallen logs or branches. Researchers have also found nymphs on the undersides of wooden park benches and tables.

Squirrel, lizards, mice, vole, fox, coyote and deer are common hosts for the western blacklegged tick. Like all ticks, migrating birds act as a long distance transporter. While the majority of cases of Lyme disease are diagnosed in the Northeast and Midwest, it is important to note that some Lyme-endemic counties in California are larger than the states of Rhode Island and Delaware, and the nymphal tick infection rate is comparable to or higher than hyperendemic areas in the northeastern U.S.



Personal Protection

Your best defense against tick-borne illness is to avoid contact with ticks in the first place. Your next best defense is to quickly find and remove any ticks that may latch on to you.

Avoid Tick Habitat

Ticks tend to be near the ground, in leaf litter, grasses, bushes and fallen logs. High risk activities include playing in leaves, gathering firewood and leaning against tree trunks. When you hike, stay on cleared trails instead of walking across grassy fields.

Dress Defensively

Wear shoes, socks, long pants and long sleeves. Tie back long hair and wear a hat. Light-colored clothing helps you spot ticks before they cause trouble.

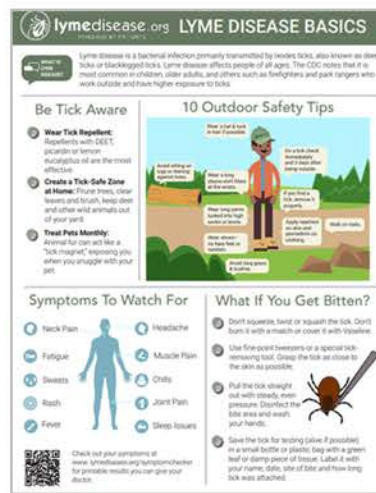
You can purchase clothing that has been pre-treated with the repellent permethrin at outdoor recreation stores and online at [Insect Shield](#). (The protection lasts through 70 washings.) Or, you can purchase [permethrin spray from Insect Shield](#) and other suppliers, and apply it to cloth-

ings.) Be sure to treat both the inside and outside of clothes.

Insect Shield also offers a [permethrin treatment service](#) that makes it easy to send your clothing to them and they will treat it with permethrin for you. With this kind of treatment, the ability to repel ticks lasts ten times longer than spray.

Use coupon code **LYMEDISEASEORG** on [InsectShield.com](#) to receive 15% off your first purchase.

When you make a purchase from Insect Shield using the coupon code or by clicking any of the links above, 10% of the proceeds will go directly to LymeDisease.org. Spraying footwear with permethrin will prevent ticks from crawling up your shoes. (In one study, those with treated shoes had 74% fewer tick bites than those with untreated shoes.)



DOWNLOAD POSTER

Use Repellent On Exposed Skin

Studies show that repellents with DEET, picaridin or lemon eucalyptus oil are the most effective.

Check For Ticks

When outdoors, periodically inspect your clothing and skin for ticks. Brush off those that aren't attached and remove any that are

Shower

Once home, take a shower right away. This will wash away unattached ticks and offer a good chance to thoroughly inspect yourself. Feel for bumps that might be embedded ticks. Pay careful attention to hidden places, including groin, armpits, back of knees, belly button and scalp. Parents should check their children.

Hot Dryer

Running your clothes in a hot dryer for 10 minutes before you wash them will kill any ticks that may be there.

Protect Your Pets

Ticks can infect dogs and cats, too. Also, their fur can act like a "tick magnet," carrying ticks inside your home. Consult with your veterinarian about tick-protection for your pets.



Tick Removal

If the tick is infected with pathogenic organisms, it can transmit the infection to the host during the feeding process. To prevent infection, it's important to remove a tick from your skin as soon as you notice it.

If A Tick Bites You:

- Don't squeeze, twist or squash it. Don't burn it with a match or cover it with Vaseline.
- Use fine-point tweezers or a special tick-removing tool. Grasp the tick as close to the skin as possible. If you don't have tweezers, protect your fingers with a tissue.
- Pull the tick straight out with steady, even pressure. [Click here](#) to view a tick's mouth and why it is so important to pull out the tick correctly.



SANITIZE BITE AREA AND TWEEZERS



GRAB TICK CLOSE TO HEAD



PULL UP SLOWLY AND CAREFULLY



SANITIZE BITE AREA AGAIN

- Disinfect the bite area and wash your hands.
- Save the tick for testing (alive if possible) in a small bottle or plastic bag with a green leaf or damp piece of tissue.
- Label it with your name, date, site of bite and how long tick was attached.

Tick Testing

If you've been bitten, you can send the tick to test and determine if the tick is carrying the pathogens that can lead to tick-borne illness to the following organizations:

- **Igenex:**
<https://igenex.com/product/tick-test/>
- **Tick Report:**
<https://www.tickreport.com/>

Whether or not you find a tick, stay alert for symptoms of tick-borne illness. A bull's-eye rash indicates Lyme disease, though not everybody with Lyme gets one. You might have a different rash or none at all. You may develop flu-like symptoms—fever, headache, nausea—or joint pain or dizziness. Consult a physician as needed.



Ticks and Landscape

The most important step you can take to rid your yard of ticks is destroying their preferred habitats. This can be as simple as mowing your lawn regularly and trimming weeds or overgrown brush.

Are There Ways To Protect Myself And My Family?

- Pruning trees
- Clearing brush
- Removing litter
- Mowing grass short, and letting it dry thoroughly between waterings.
- Move shrubbery and overgrowth farther away from areas frequented by people.



Make your property unattractive to animals that are hosts to ticks by:

- Eliminating birdfeeders, birdbaths and salt licks;
- Erecting fencing around the property;
- Clearing away woodpiles, garbage and leaf piles;
- Removing stonewalls that provide homes to wildlife.
- Having your property chemically treated.

Seek professional advice before applying chemicals to kill ticks. Carefully-timed applications increase effectiveness.

[The Tick Management Handbook](#) is a guide for homeowners, pest control operators and public health officials from the Connecticut Agricultural Experiment Station. It provides information on ticks, diseases, personal protection, prevention, how to prepare your landscape and chemical controls. [Click here](#) to download it.



03 Lyme Basics

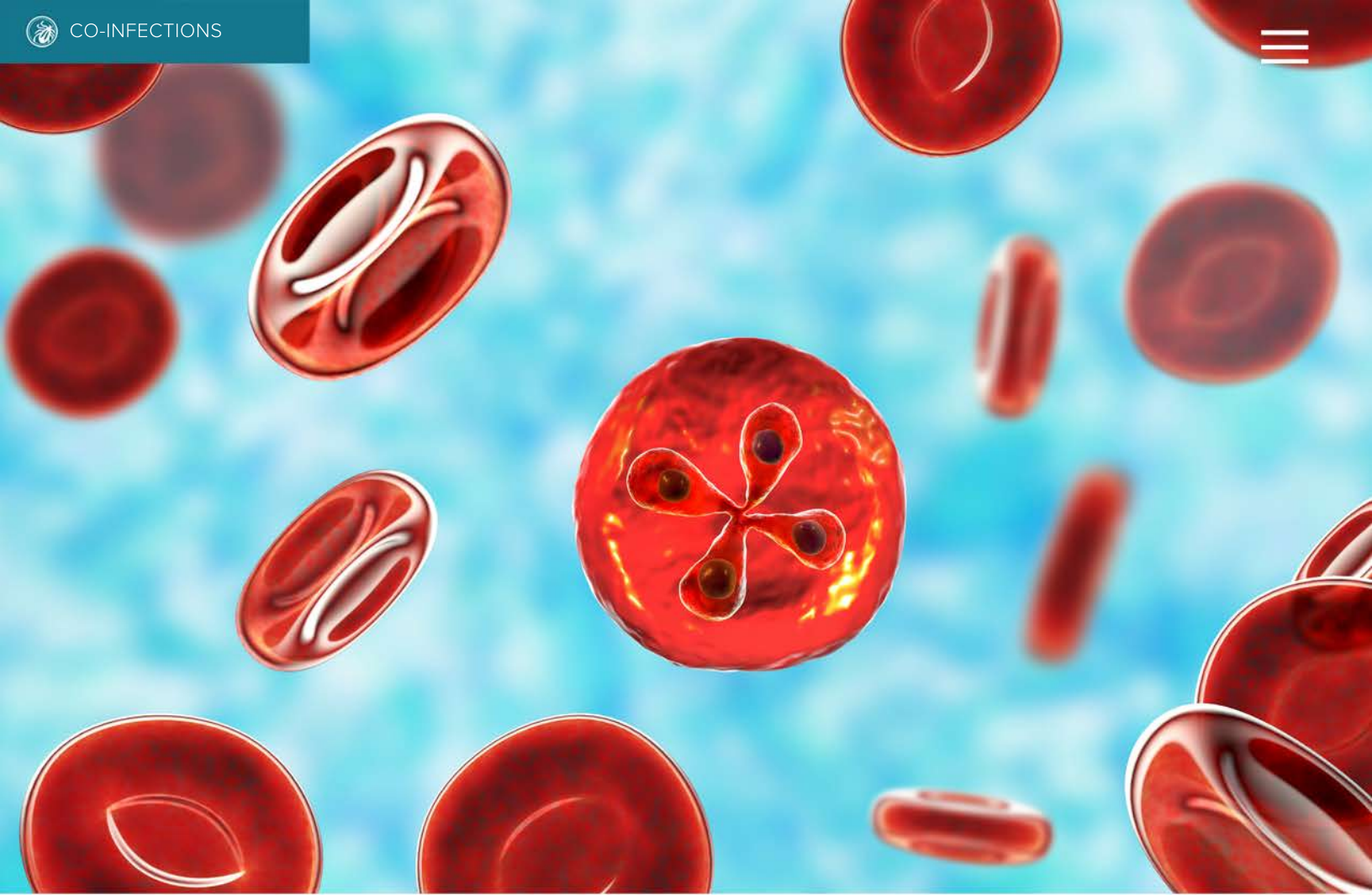
Co-Infections

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- 11 Other Lyme Disease Co-Infections



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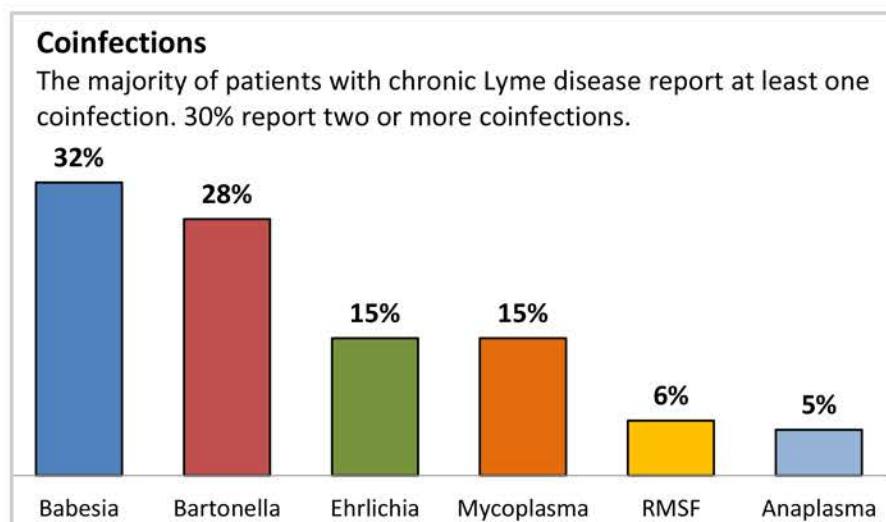
About Lyme Disease Co-Infections

The most common tick-borne diseases in the United States include Lyme disease, babesiosis, anaplasmosis, ehrlichiosis, relapsing fever, tularemia, Rocky Mountain spotted fever (RMSF). Diseases acquired together like this are called co-infections.

Tick-borne infections are zoonotic—meaning they are passed from animals to humans. “Vectors” like ticks, mosquitos and fleas transmit the diseases from animals like mice, rats, and squirrels to humans when they bite. Ticks can carry many bacteria, viruses, fungi and protozoans all at the same time and transmit them in a single bite. The most common tick-borne diseases in the United States include Lyme disease, babesiosis, anaplasmosis, ehrlichiosis, relapsing fever, tularemia, Rocky Mountain spotted fever (RMSF). Diseases acquired together like this are called co-infections. Below are Lyme disease co-infections which you will learn more about in the pages that follow..

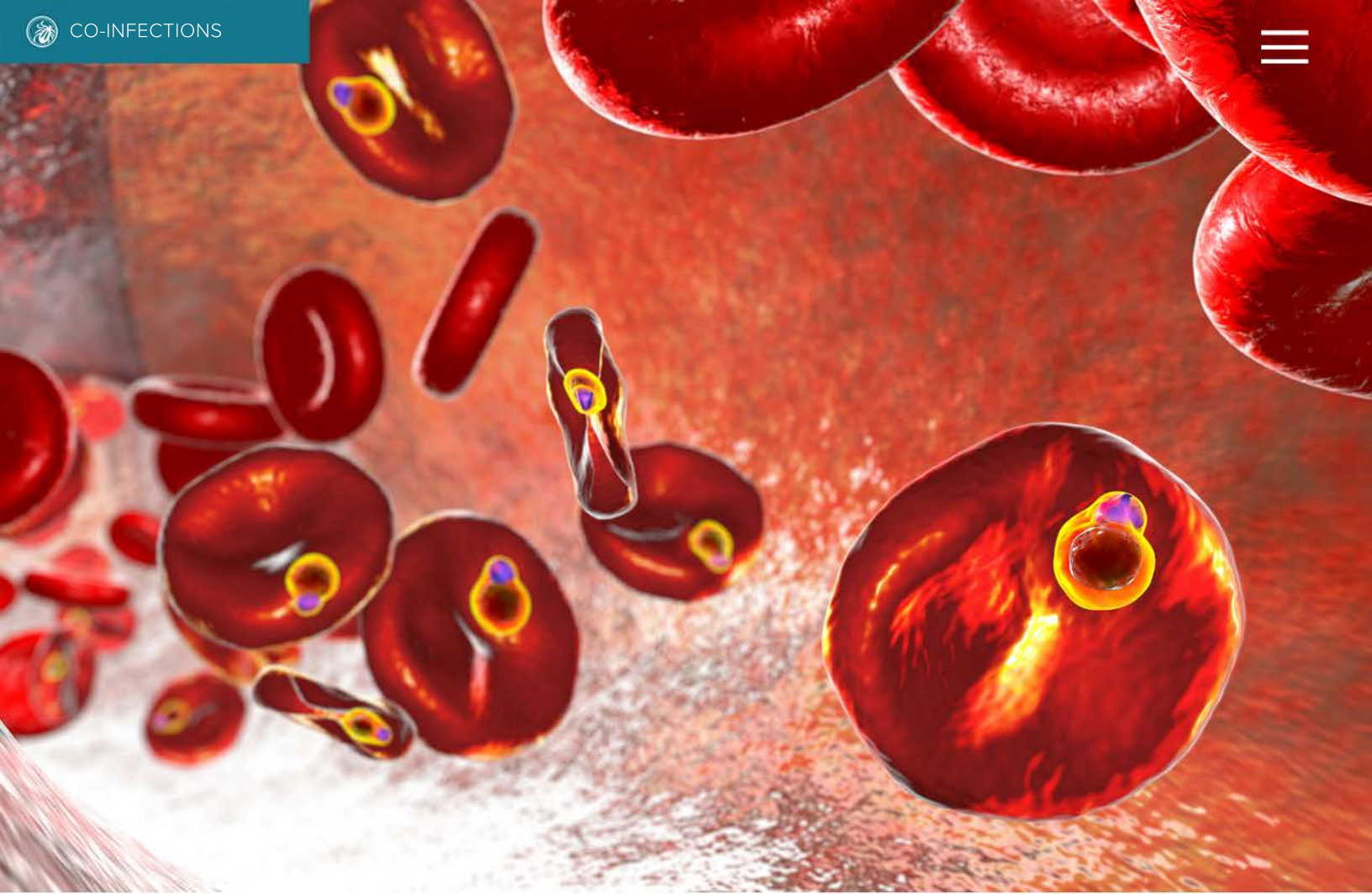
- Babesia
- Ehrlichia and Anaplasma
- Bartonella
- Other Lyme Disease Co-Infections
- Rickettsia

Coinfections may be common – at least among those with chronic Lyme disease. A recently published [LDo survey](#) over 3,000 patients with chronic Lyme disease found that over 50% had coinfections, with 30% reporting two or more coinfections. The most common coinfections were Babesia (32%), Bartonella (28%), Ehrlichia (15%), Mycoplasma (15%), Rocky Mountain Spotted Fever (6%), Anaplasma (5%), and Tularemia (1%). A [similar study](#) in Canada found similar rates of coinfection in patients with chronic Lyme disease:



A person with a co-infection generally experiences more severe illness, more symptoms, and a longer recovery. The CDC recommends that physicians consider possible co-infection with babesia or anaplasma when patients have more severe symptoms of Lyme disease. However, other co-infections may be present as well.

Since Lyme disease was first identified in 1981, researchers have found more than 15 tick-borne pathogens that weren't known before. New ones are still being discovered. In 2011, *Borrelia miyamotoi* was identified as a cause of disease and recently recognized by the CDC in the United States. Commercial tests are not available for all tick-borne diseases, including infection with *B. miyamotoi* or Powassan virus.



Babesiosis

Babesiosis is a disease caused by infection with Babesia. Babesia is a malaria-like parasite, also called a “piroplasm,” that infects red blood cells. Scientists believe Babesia microti is the most common piroplasm infecting humans, but they have identified over twenty piroplasms carried by ticks.

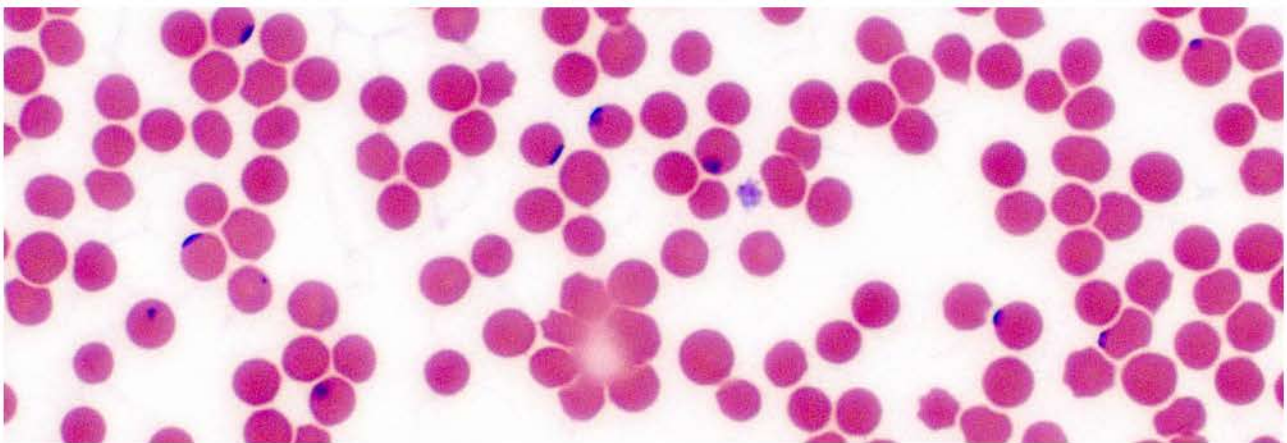
Babesia is a malaria-like parasite

Babesiosis is a disease caused by infection with Babesia. Babesia is a malaria-like parasite, also called a “piroplasm,” that infects red blood cells. Scientists believe Babesia microti is the most common piroplasm infecting humans, but they have identified over twenty piroplasms carried by ticks. In addition to transmission by a tick, babesia can be transmitted from mother to unborn

child or through a contaminated blood transfusion. Currently, most blood banks do not screen donated blood for babesia.

The First Case Of Babesiosis

The first case of babesiosis was reported from Nantucket Island, Massachusetts, in 1969. Since the late 1980s, the disease has spread from the islands off the New England coast to the mainland. Cases have also been reported across the United States, Europe, and Asia.



Symptoms Of Babesiosis

Symptoms of babesiosis are similar to those of Lyme disease but babesiosis more often starts with a high fever and chills. As the infection progresses, patients may develop fatigue, headache, drenching sweats, muscle aches, chest pain, hip pain and shortness of breath (“air hunger”). Babesiosis is often so mild it is not noticed but can be life-threatening to people with no spleen, the elderly, and people with weak immune systems. Complications include very low blood pressure, liver problems, severe hemolytic anemia (a breakdown of red blood cells), and kidney failure.

Diagnosis and Treatment

Sometimes, babesia can be detected in blood examined under a microscope. However, this method is reliable only in the first two weeks of the infection. Commercial tests currently detect only two strains of Babesia and there are likely many strains yet to be discovered. The PCR (polymerase chain reaction) test can detect babesia DNA in the blood. The FISH (Fluorescent In-Situ Hybridization) assay can detect the ribosomal RNA of Babesia in thin blood smears. The lab can also test the patient’s blood for antibodies to Babesia. It may be necessary to run several different tests, and negative results should not be used to rule out treatment.

Babesiosis is typically treated with a combination of anti-malarial drugs and antibiotics. Relapses sometimes occur after treatment and must be retreated.



Bartonella

Bartonella are bacteria that live primarily inside the lining of the blood vessels. They can infect humans, mammals and a wide range of wild animals. The disease that results is called bartonellosis. Bartonella bacteria are known to be carried by fleas, body lice and ticks, and there's high suspicion that ticks transmit it to humans.



Bartonella results in a disease called Bartonellosis

Bartonella are bacteria that live primarily inside the lining of the blood vessels. They can infect humans, mammals and a wide range of wild animals. The disease that results is called bartonellosis.

Bartonella henselae causes an important emerging infection that was first reported in 1990. It is mainly carried by cats and causes cat-scratch disease, endocarditis, and several other serious diseases in humans.

Transmission Of The Bartonella Bacteria

Bartonella bacteria are known to be carried by fleas, body lice and ticks, and there's high suspicion that ticks transmit it to humans. People with tick bites and no

known exposure to cats have acquired the disease. People who recall being bitten by ticks have been co-infected with the Lyme spirochete and bartonella. Scientists have recently established that ticks can transmit Bartonella to mice. More research needs to be done to establish the role of ticks in spreading the disease. In addition, a recent study suggests that bartonella may be passed from mother to unborn child (perinatal transmission).

Several Species Of Bartonella

Scientists have identified several species of bartonella. Sand flies in the Andes Mountains in Peru, Colombia, and Ecuador carry one type. Human body lice worldwide carry another.



Bartonellosis Symptoms

Historically, bartonellosis has been described as a mild, acute, and self-limiting illness. However, more and more doctors recognize that bartonella can cause chronic infection. Patients may suffer relapses because bartonella periodically cycles into red blood cells, which may provide a protective niche for the bacteria.

Early signs of bartonellosis include fever, fatigue, headache, poor appetite, and an unusual streaked rash that resembles “stretch marks” from pregnancy. Swollen glands are typical, especially around the head, neck and arms. Patients with bartonellosis report more neurological symptoms and are more likely to have visited a neurologist than members of the general population. Some common symptoms include blurred vision,

numbness in the extremities, memory loss, balance problems, headaches, ataxia (unsteady gait), and tremors. Bartonellosis also sometimes triggers psychiatric manifestations.

Bartonellosis Diagnosis and Treatment

Polymerase chain reaction (PCR) and tissue biopsy can be used. However they are also insensitive, as are standard blood tests. Dr. Ed Breitschwerdt, a professor of Veterinary Science at North Carolina State University who has studied bartonellosis extensively, notes that tests for the bacteria may be negative one time and positive another.

Fluoroquinolones and doxycycline are sometimes successful in treating bartonellosis. However, some doctors report the need to use several antibiotics in combination.



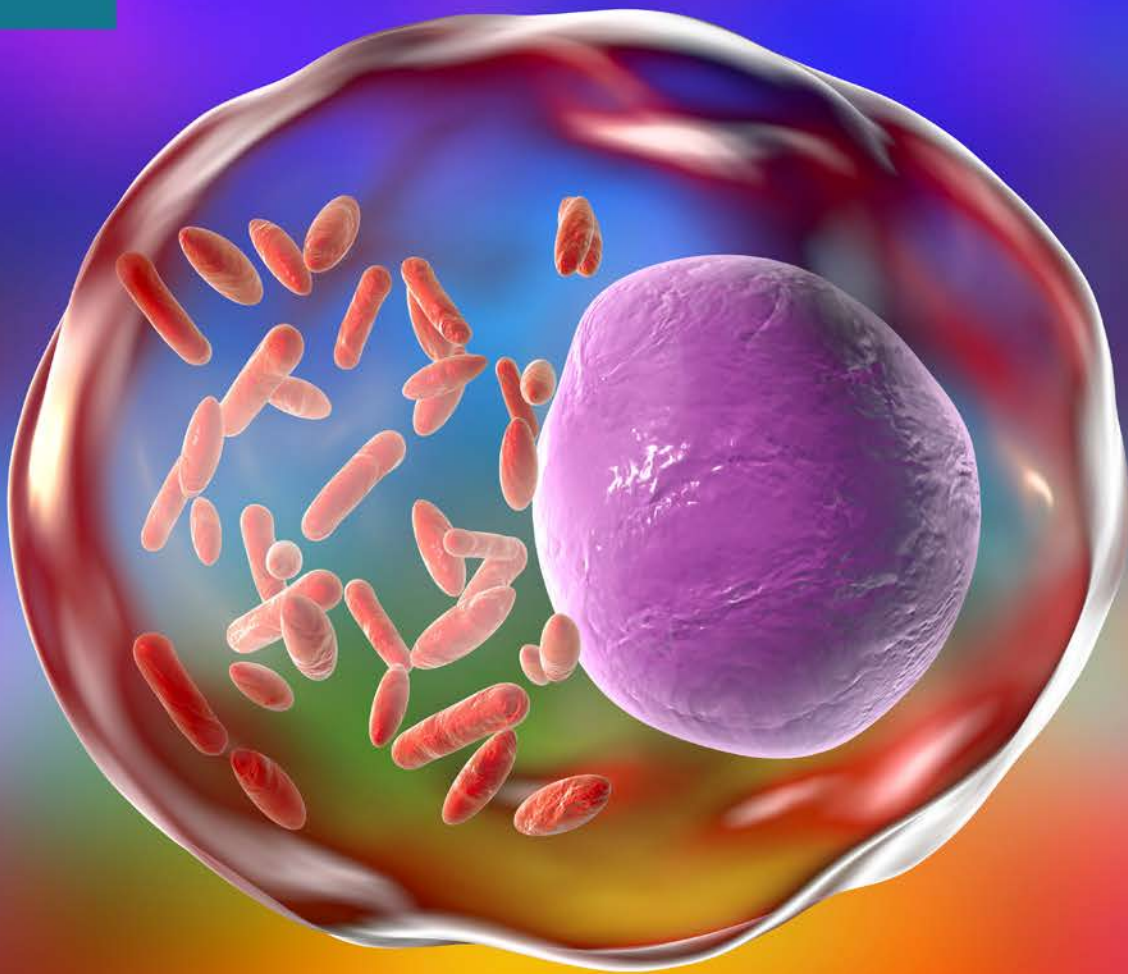
Symptoms

The clinical manifestations of ehrlichiosis and anaplasmosis are the same. Each is often characterized by sudden high fever, fatigue, muscle aches, headache. The disease can be mild or life-threatening. Severely ill patients can have low white blood cell count, low platelet count, anemia, elevated liver enzymes, kidney failure and respiratory insufficiency. Older people or people with immune suppression are more likely to require hospitalization. Deaths have occurred.

Diagnosis And Treatment

Diagnosis is limited by our current ability to test for only two species. Ehrlichia parasites multiply inside host cells, forming large mulberry-shaped clusters called morulae that doctors can sometimes see on blood smears. The infection still can easily be missed. The doctor may suspect ehrlichiosis/anaplasmosis in a patient who does not respond well to treatment for Lyme disease.

The treatment of choice for ehrlichiosis/anaplasmosis is doxycycline, with rifampin recommended in case of treatment failure. In resistant or complicated cases, combination antibiotic therapy may be necessary to eradicate the infection.



Rickettsia

Some particularly troublesome bacteria belong to a group called Rickettsia. Although they can also be found in lice, fleas, mites and chiggers, in the US, most rickettsial infections are thought to be transmitted by ticks. Rickettsia includes two different groups: the spotted fever group (which consists of rickettsiae and ehrlichia) and the typhus group.

The spotted fever group rickettsiae (SFGR) includes:

- **Rickettsia Rickettsii**, Also Known As Rocky Mountain Spotted Fever (RMSF)
- **Rickettsia Parkeri**
- **Rickettsia Philipii**, (Previously 364D) The Cause Of Pacific Coast Tick Fever
- **Rickettsia Helvetica*** (Which May Be Found In The U.S.)

**Rickettsia helvetica* was discovered by Dr. Willy Burgdorfer in 1978, and widely thought to be found only in Europe. However, it was recently uncovered in Burgdorfer's 35-year-old archives that he had seen a bacterium that highly resembled *R. helvetica* inside the samples of blood containing *Borrelia* (the bacteria that causes Lyme disease). He called this microbe the "Swiss Agent." ([Read more about Rickettsia helvetica discovery.](#))

Rocky Mountain Spotted Fever

Rocky Mountain spotted fever (RMSF) is the most common rickettsial infection in the U.S. It can range from a mild illness to a fatal one.

Initial symptoms typically include high fever, severe headache, abdominal pain (with or without vomiting), and muscle pain. It often—though not always—includes a spotted rash that begins at the wrist and/or ankles, and spreads outward from there.

The progression of Rocky Mountain Spotted Fever varies greatly between patients. Some may recover quickly on oral medications, while others may require intravenous antibiotics, prolonged hospitalization or intensive care.

RMSF weakens small blood vessels throughout the body, giving rise to its characteristic rash. This widespread damage to the blood vessels allows the bacteria to spread to the heart and brain—and can quickly lead to death in those under age 4, over the age of 60, or those whose immune systems are compromised.



Rickettsia Rash

Prior to the use of antibiotics, Rocky Mountain Spotted Fever had a fatality rate of up to 80%. In the U.S. today, the fatality rate is 5%-10%. However, in neighboring Mexico, fatality rates from RMSF in recent years have been as high as 30%.

Rickettsia In Dogs

An interesting case study occurred in eastern Arizona, where there are no known American dog ticks (the primary vector of RMSF). Beginning in 2003, there were outbreaks of Rocky Mountain Spotted Fever on several Indian reservations, with the rate of infection reaching 150 times the national average, including 19 fatalities. This was later attributed to the large population of

free-roaming dogs. Unexpectedly, the brown dog tick was identified as the vector in these cases.

Community leaders and public health officials dramatically reduced the rate of RMSF by treating the yards of 500 homes with acaricide (pesticides which target ticks) and placing long-acting tick collars on over 1000 dogs.

Afterwards, ticks were only found on 1% of the dogs with collars versus 64% of the untreated dogs. These collaborative efforts helped reduce Rocky Mountain Spotted Fever by 43% on the reservations.

Other Types Of Rickettsiosis Infections

Rickettsia parkerii, found along the Gulf Coast, and *R. phillipii*, from the West Coast, cause a milder form of rickettsiosis. The spotted rash is not as common but both will frequently cause an eschar (scab) or necrotic area about one centimeter across, at the site of the tick bite. These other types of rickettsiosis usually result in a mild illness that may go undiagnosed. Thus, the actual number of infections may be higher than we know.

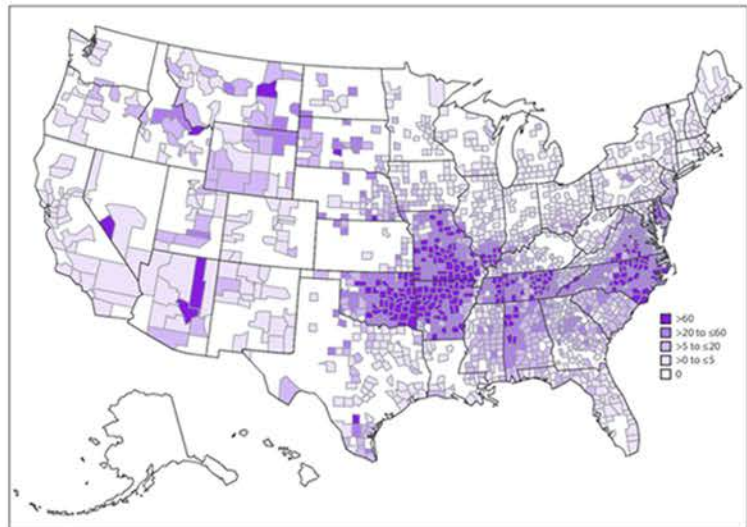
Rickettsia Transmission

In the United States, Rickettsiosis is primarily transmitted by the following ticks:

- **American dog tick**, (*Dermacentor variabilis*)
- **Rocky Mountain wood tick**, (*Dermacentor andersoni*)
- **Brown dog tick**, (*Rhipicephalus sanguineus*)
- **Gulf Coast tick**, (*Amblyomma maculatum*)
- **Pacific Coast ticks**, (*Dermacentor occidentalis*)

Incidence of Spotted Fever Rickettsiosis

Reported to CDC by County 2000 - 2013



* As reported through national surveillance, per 1,000,000 persons per year. Cases are reported by county of residence, which is not always where the infection was acquired.

+ Includes Rocky Mountain spotted fever (RMSF) and other spotted fever group rickettsioses. In 2010, the name of the reporting category changed from RMSF to spotted fever rickettsiosis.

Rickettsia Distribution

According to the CDC, rickettsial diseases have been reported in every state except Alaska and Hawaii, where they are not yet notifiable (so nobody is keeping track). 60% of SFGR cases are reported in five states: North Carolina, Oklahoma, Arkansas, Tennessee, and Missouri.

Rickettsia Incidence

In 2009, the reporting definition for Rocky Mountain Spotted Fever was changed to include the more broad “Spotted Fever Rickettsiosis” (SFR) which includes RMSF. Using the new criteria, there were 4470 reported cases of spotted fever rickettsiosis in 2012, the majority of which were presumed to be RMSF. In general, the cases of SFR are increasing—from 1.7 cases per million in 2000 to an all-time high of 14.2 cases per million in 2012.

Summary of Spotted Fever Rickettsiosis Found in U.S.

Disease	Incubation period	Initial signs and symptoms	Cutaneous signs (skin)	Laboratory findings	Estimated Case- fatality rate
Rocky Mountain spotted fever	3-12 days	Fever, headache, chills, malaise, myalgia, nausea, vomiting, abdominal pain, photophobia, anorexia,	Maculopapular rash 2-4 days after onset in most, might become petechial and involve palms and soles of feet	Thrombocytopenia, slight increased hepatic transaminase levels, normal or slight increase white blood cell count with increase neutrophils, hyponatremia	5% - 10%
Rickettsia parkeri rickettsiosis	2-10 days	Fever, myalgia, headache	Eschar, sparse maculopapular or vesiculopapular rash that might involve palms and soles	Mild thrombocytopenia, mild leukopenia, increased hepatic transaminase levels	none known
Rickettsia 364D Pacific Coast Fever	not known	Fever, headache, myalgia, fever	Eschar or ulcerative lesion with regional lymphadenopathy	not known	not known



Ehrlichia and Anaplasma

Ehrlichiosis is a term that describes several different bacterial diseases, one of which is also called anaplasmosis. Some are transmitted by Ixodes ticks and others by the lone star tick.



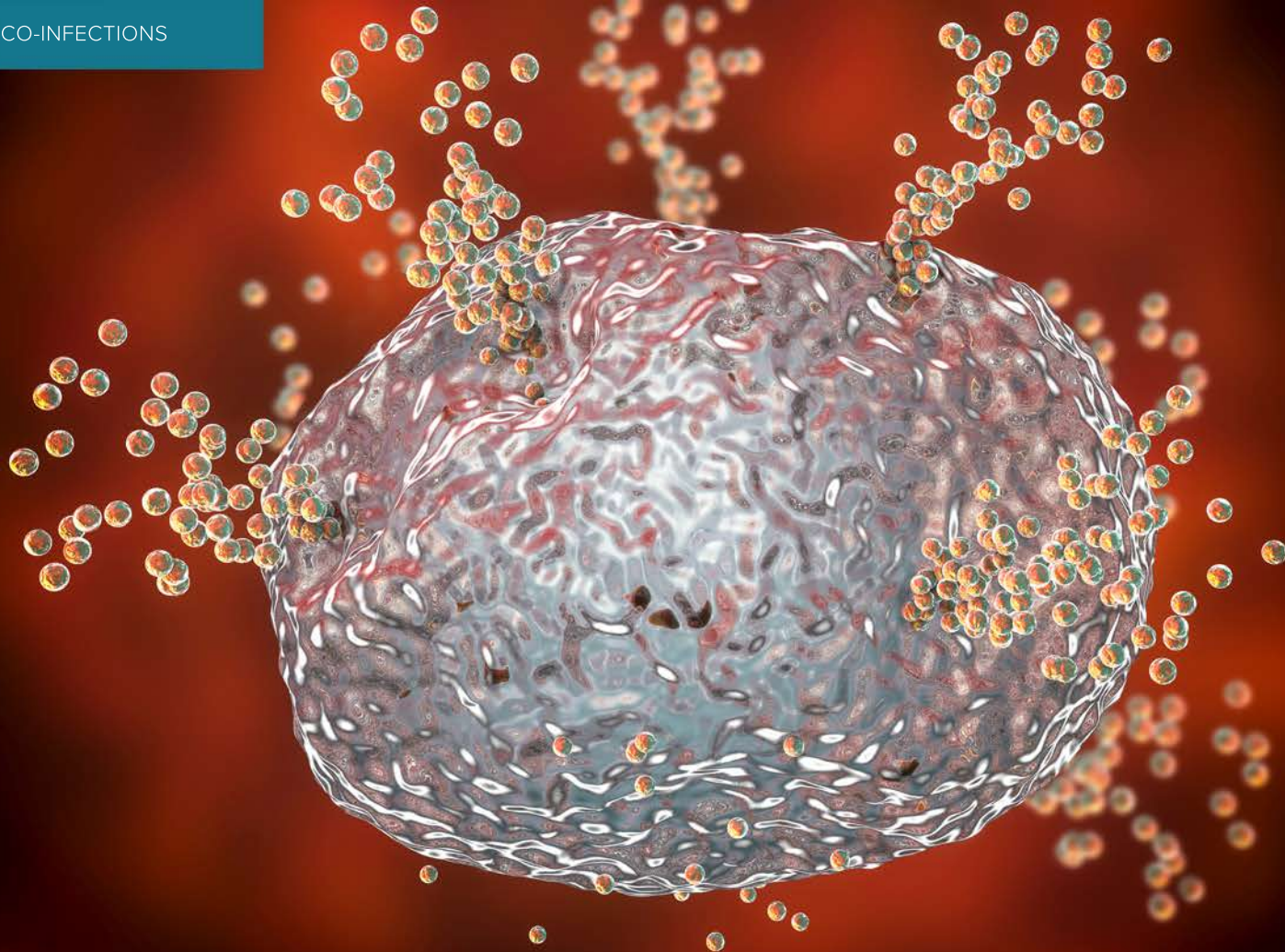
Symptoms

The clinical manifestations of ehrlichiosis and anaplasmosis are the same. Each is often characterized by sudden high fever, fatigue, muscle aches, headache. The disease can be mild or life-threatening. Severely ill patients can have low white blood cell count, low platelet count, anemia, elevated liver enzymes, kidney failure and respiratory insufficiency. Older people or people with immune suppression are more likely to require hospitalization. Deaths have occurred.

Diagnosis And Treatment

Diagnosis is limited by our current ability to test for only two species. Ehrlichia parasites multiply inside host cells, forming large mulberry-shaped clusters called morulae that doctors can sometimes see on blood smears. The infection still can easily be missed. The doctor may suspect ehrlichiosis/anaplasmosis in a patient who does not respond well to treatment for Lyme disease.

The treatment of choice for ehrlichiosis/anaplasmosis is doxycycline, with rifampin recommended in case of treatment failure. In resistant or complicated cases, combination antibiotic therapy may be necessary to eradicate the infection.



Mast Cell Activation Syndrome

Many Lyme patients find they develop serious allergic reactions to foods, medications and cleaning chemicals that they used to be able to tolerate with no problem. This can be a sign of mast cell activation syndrome, a newly recognized condition that is one of several mast cell activation diseases often abbreviated “MCAD.”

According to Dr. T.C. Theoharides, an expert in the field, “Mast cells are ‘universal alarm cells’ that start the inflammatory cascade. They can be triggered by infection, allergens, environmental factors like pollution, or even emotional stress. Once that happens, mast cells set into motion a series of inflammatory reactions, including the activation of immune cells and the release of tumor necrosis factor-alpha (TNF-a), a pro inflammatory protein or cytokine.”

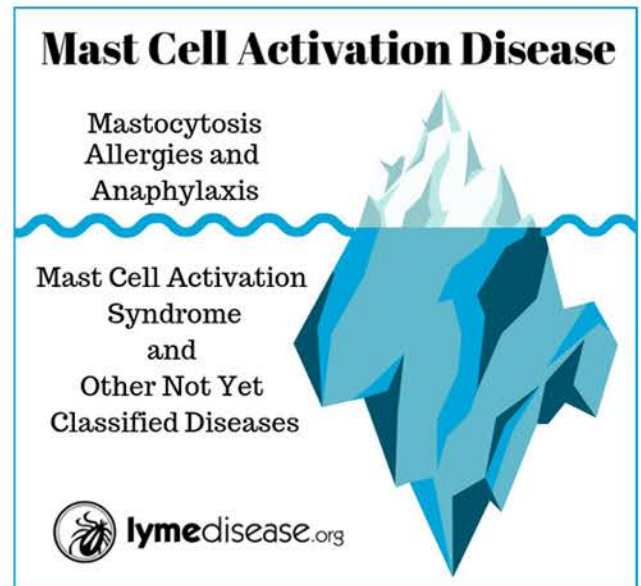
Mast Cell Activation Diseases

Mast cells are a normal part of our immune system. They live in the bone marrow, flow through our blood stream and are located in every organ and connective tissue of the body. When mast cells detect stress, injury, toxins or infection, they release specific chemicals (mediators) which trigger an immune response. Think of them as sentries or guards.

When mast cells perform properly, they help us. When mast cells are agitated or over-reactive, the immune system goes haywire and starts to attack the body, triggering auto-inflammatory processes.

There are two major forms of mast cell activation diseases

1. Mastocytosis — the abnormal accumulation of mast cells in one or more organ systems (cardiovascular, central nervous, digestive, endocrine, genitourinary, lymphatic, muscular, peripheral nervous, respiratory, dermatologic) which is diagnosed by a bone marrow biopsy or a genetic test.



2. Mast cell activation syndromes

(MCAS) — the inappropriate release of mast cell mediators including: histamine, interleukins, prostaglandins, cytokines, chemokines, and heparin (There are more than 200 chemical mediators associated with mast cells.)

Up until recently, mast cell disease was thought to only include mastocytosis, a rare condition recognized in the medical literature since 1869. It wasn't until 1988 that the first papers of “disorders of mast cell activation” were published, and nearly another 20 years later, in 2007, before the first case reports of mast cell activation syndrome came out.

As more information is learned about MCADs, researchers are finding that mastocytosis is really just the tip of the iceberg for mast cell diseases. MCAS is currently considered an ‘emerging’ illness, not because it is a new disease, but emerging from a lack of recognition and understanding.

Symptoms of MCAS

Some patients report years of having various allergic-type reactions to assorted substances. Then, a particular triggering event leads to a cascade of increasing symptoms. For example, somebody might have sensitivities to a few foods over several years. Then suddenly, anything they eat causes a bad reaction.

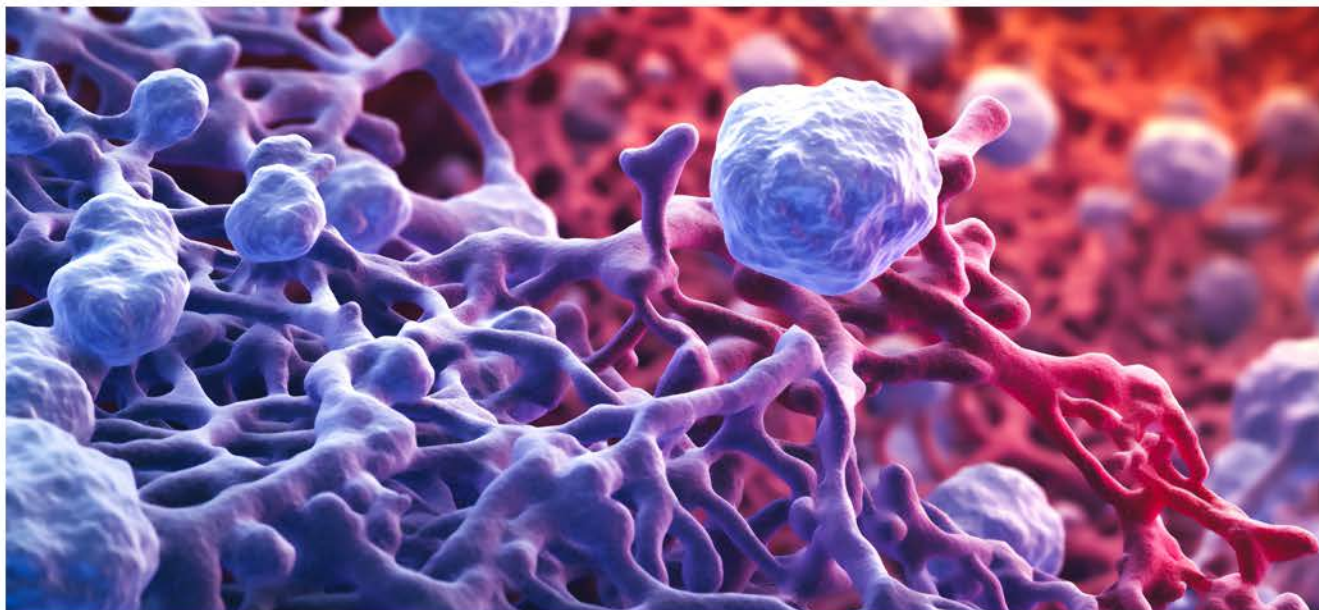


Potential triggers of MCAS:

- **Infection:** *bacteria, fungi, parasite, virus*
- **Insect bites:** *spiders, ticks, fleas, mosquitos, bed bugs*
- **Foods:** *dairy, fermented or aged food, wheat, shell fish, sugar, preservatives*
- **Drugs:** *alcohol, hormones, opioids, medications and/or fillers in medications*
- **Dyes:** *food coloring, radiographic dyes, pigments in makeup*
- **Environmental:** *sun exposure, temperature and/or pressure changes, pollen, dust, mold, animal dander, heavy metals, pesticides*
- **Noxious odors:** *perfumes, smoke, exhaust fumes, smog, cleaning supplies*

MCAS can affect many body systems:

- **Abdominal:** *pain, diarrhea and/or constipation, gastritis, reflux, nausea, irritable bowel*
- **Cardiovascular:** *high and/or low blood pressure, POTS, rapid heart rate, loss of consciousness, palpitations*
- **Skin:** *hives, rashes, flushing, swelling, edema, hive-like welt reaction when skin is scratched (dermatographic urticaria) also called skin writing*
- **Eyes/Ears:** *dry, itching or burning eyes, conjunctivitis, watery eyes, visual disturbance, ringing in the ears, hypersensitivity to light or sound*



MCAS can affect many body systems:

- **Genital/Urinary:** *endometriosis, ovarian cysts, painful bladder*
Growth and development: delayed puberty, poor healing, cysts, fibrosis, endometriosis, connective tissue disorders, osteoporosis
- **Liver:** *enlarged spleen, elevated cholesterol, liver enzymes or bilirubin.*
- **Lungs:** *cough, asthma-like symptoms, shortness of breath, wheezing, anaphylaxis*
- **Nodes:** *enlarged lymph nodes*
- **Nervous system:** *headache, pain, poor concentration/memory, anxiety, insomnia, dizziness, migratory pain and/or numbness, wide range of psychiatric disorders*
- **Oral/Nasal:** *sores, burning pain, itching, sneezing, runny nose, difficulty swallowing*

Diagnosis of Mast Cell Activation Syndrome

Because MCAS is a relatively new diagnosis, there are very few laboratory tests available. A diagnosis of MCAS should be made by a practitioner who is familiar with the condition, and be based upon a person's clinical history and symptoms, response to medications and confirmatory lab work. (Complete guide to the of mast cell activation syndrome.)

Treatment for Mast Cell Activation Syndrome

The Mastocytosis Society, a nonprofit organization dedicated to supporting patients affected by mast cell activation diseases, offers a list of physicians who provide care for patients with these conditions.

For more information about mast cell activation syndrome and how one family solved this problem, we recommend you read this series of posts in our LYME SCI blog. ([More about mast cell activation syndrome](#))



Alpha-gal Syndrome

There is growing evidence that certain types of tick bites can trigger alpha-gal syndrome (AGS) a life-threatening allergy to red meat and meat-related products. In some individuals, it appears tick bites can result in the sensitization to a carbohydrate known as galactose-alpha-1,3-galactose, or “alpha-gal” for short. This sugar molecule is found in most mammals you might be likely to eat, but not in fish or fowl.

Most recognized food allergies, such as to peanuts or shellfish, will prompt an immediate reaction after being consumed. That's not the case with AGS, however, which can take up to eight hours (or even more) after exposure to produce a reaction.

What can bring on a reaction?

- **Commonly consumed mammalian meats** that contain alpha-gal include beef, pork, lamb, goat, venison and buffalo.
- **Common foods that are derived from mammals** include lard, milk, cream, ice cream, and cheese—although the majority of AGS patients do tolerate dairy products.
- **Personal products** that use ingredients containing “hydrolyzed protein” (gelatin), lanolin, glycerin, collagen, or tallow are particularly problematic.
- **Additional products** that can bring on an alpha-gal reaction are jello, gelatin capsules, certain medications, pig or cow heart valves, surgical mesh, certain vaccines and unlabeled “natural flavorings” in foods.
- **Some people with AGS also react to carrageenan**, a common food additive made from red algae, which also contains alpha-gal. (So even being strictly vegan won't necessarily protect you from AGS reactions.)

How are ticks involved in alpha-gal syndrome?

Alpha-gal meat allergy has been reported all over the world including Asia, Australia, Central America, Europe, Germany, Japan, South Korea, and the United States.

In the U.S., the tick species most often associated with AGS is the lone star tick (*Amblyomma americanum*) found throughout the South, East and parts of



the Midwest. Recent research suggests that the blacklegged tick (*Ixodes scapularis* and *Ixodes pacificus*) may also be implicated in alpha-gal syndrome.

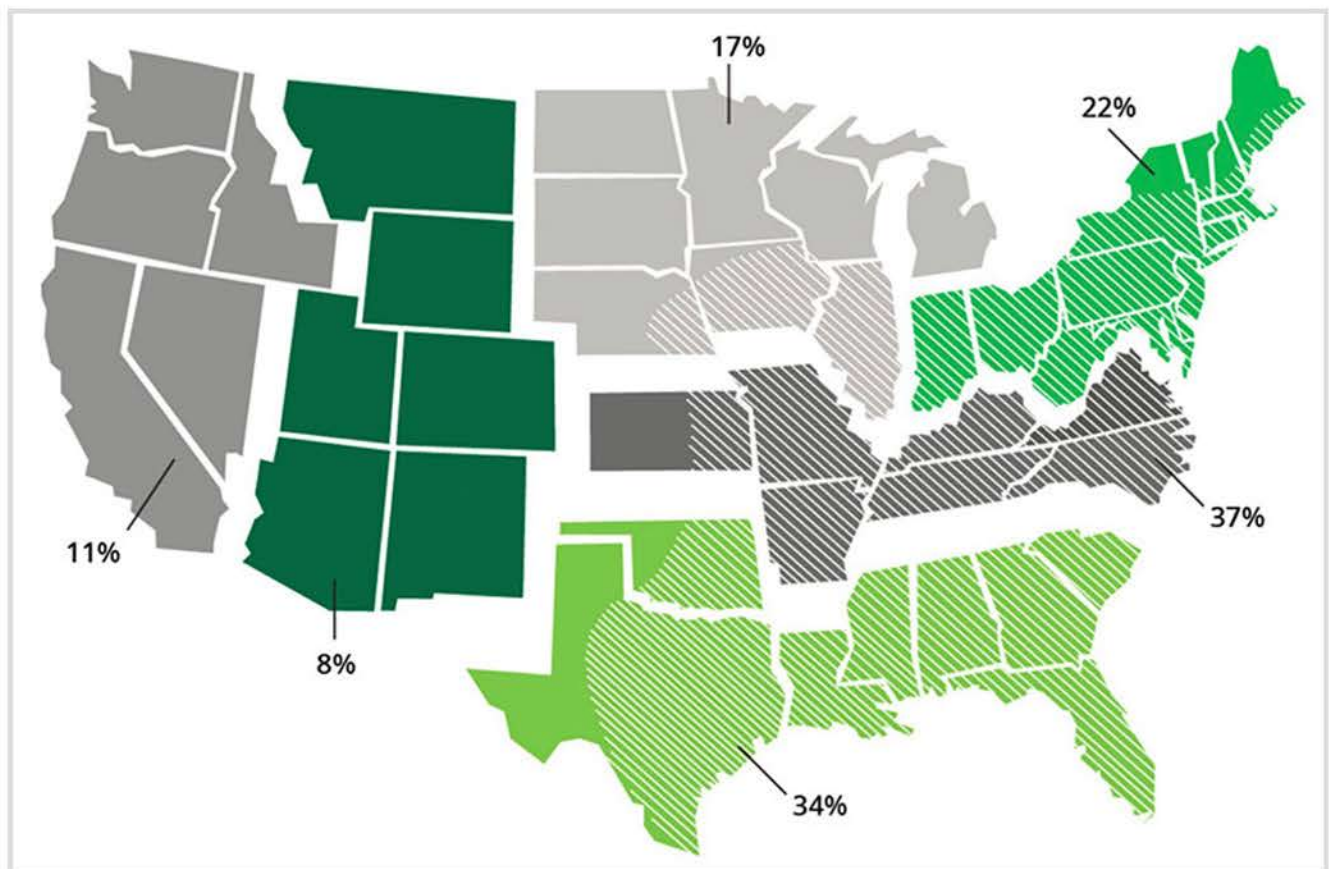
The Asian longhorned tick (*Haemaphysalis longicornis*), the primary trigger of AGS in Asia, has shown up in the US recently, but has yet to be implicated in AGS here. The Cayenne tick (*Amblyomma cajennense*) found in southern Texas and Florida has also been linked to AGS in Central America, but not yet in the U.S.

While no known pathogen has been linked to triggering AGS, more research is needed to understand the mechanism and the role that ticks play. Currently the thought is that the tick saliva plays a role in activating the allergy to alpha-gal.

Who's at risk for AGS?

Alpha-gal syndrome is a much more common allergy in the U.S. today than it was a decade ago, with the number of laboratory-confirmed cases growing from 12 in 2009 to over 34,000 in 2019. Unfortunately, AGS has no insurance billing code (ICD code), nor is it a reportable illness to the CDC.

Experts agree alpha-gal syndrome is under-reported in geographic areas where tick bites are common.



Surveillance for IgE to alpha-gal. Percent positive rates are presented for IgE to alpha-gal within each of six regions in the United States, 2012-2013 (7300 samples). Diagonal white lines on the map represent the known geographic distribution of the lone star tick (Data and map, Viracor-IBT Laboratories; Tick Distribution, CDC).

Biggest risk factor for AGS

For now, the biggest risk factor for AGS appears to be repeated bites by ticks that contain alpha-gal in their saliva and salivary glands. It is not understood why, but not everyone who is bitten by a tick containing alpha-gal will develop AGS.

While both children and adults can acquire AGS, most cases have been reported in adults.

Certainly, if a patient with recent tick exposure presents with sudden onset anaphylaxis and recurrent gastrointestinal symptoms, AGS should be considered.

What are the symptoms of alpha-gal syndrome?

The symptoms of alpha-gal syndrome are often delayed, making it much harder to pinpoint the trigger. Someone may wake up at 3 o'clock in the morning in the throes of serious allergic reaction, and have no idea it was brought on by a hamburger they ate the night before.

Symptoms can range from itching and stomach upset to breathing difficulty and full anaphylaxis. AGS reactions often start with itching of the palms of hands and soles of feet.

Common symptoms of AGS include:

- **90% have skin symptoms:** itching “pruritus,” flushing “erythema,” hives “urticaria” (swollen, pale red bumps or “wheals” on the skin), angioedema (swelling in deep layers below the skin)
- **60% develop anaphylaxis** (a potentially deadly reaction that can restrict breathing)



- **60% have gastrointestinal symptoms** (abdominal pain, diarrhea, acid reflux, cramping, vomiting)
- **30-40% experience cardiac symptoms:** rapid decrease in blood pressure (hypotension, POTS); palpitations (atypical chest symptoms)
- **30-40% experience respiratory symptoms** (wheezing, coughing, shortness of breath)
- **20% of patients will have GI symptoms alone** (may present like irritable bowel syndrome)
- **3-5% develop mast cell activation syndrome**
- **arthritis** (rare)
- **mouth swelling, sores** (rare)

How is AGS diagnosed?

If you experience symptoms after eating mammalian meat products, immediately notify your primary care physician or allergist. Unlike most tick-borne pathogens, the onset of AGS usually takes at least 4-6 weeks from the time of the tick bite. Complicating things further, about a third of patients do not recall a tick bite.

Your doctor should be able to determine if you have AGS based upon your clinical symptoms and a positive blood test: immunoglobulin E (IgE) to the oligosaccharide galactose-alpha-1,3 galactose (alpha-gal.)

In the U.S., [Viracor is the main laboratory](#) for AGS testing. The Viracor “specific IgE galactose-alpha-1,3-galactose” test can be taken at most commercial laboratories like Labcorp and Quest and shipped to Viracor.

Warning: The test for alpha-gal is often mistaken for “alpha-galactosidase” or “a-galactosidase A deficiency”—note these are the wrong tests! Because the test is so new, it is recommended to take the proper testing codes with you to the doctor and the laboratory. [Click here](#) to download and print a PDF on the proper testing codes for alpha-gal syndrome.

How is Alpha-gal syndrome treated?

There are currently no U.S. FDA-approved medications for the treatment of AGS. As with most allergies, the mainstay of management is avoidance of the allergen.



Therefore, the best practice is to avoid exposure to:

- 1. Mammalian meats**
- 2. Personal products** containing mammalian derivatives
- 3. Medical products** containing mammalian proteins, derivatives or parts
- 4. Medications** containing mammalian proteins or derivatives

Knowing you must avoid mammalian products is only half the battle, as these products have worked their way into nearly every level of our modern life.

For instance, gelatin is the main ingredient of jellybeans, candy corn, marshmallows, puddings and the capsules of many medications. Chicken and turkey sausages may be stuffed in pork casings, lard (rendered pork fat) is found in many pre-made gravies, sauces, soups, candies, chips, fries, and more.

As with all serious allergies, it is important to have the proper diagnosis and be prepared with how to respond in the event of an emergency. Most allergists will recommend wearing a medical alert bracelet and carrying an EpiPen and an antihistamine with you at all times.

Avoiding alpha-gal hidden components

Mammalian proteins and parts can be found in many medications and medical products. . Because the source of many ingredients is not listed on product labels, your pharmacist may need to contact the manufacturer. Have your pharmacist ask specifically if it contains galactose-alpha-1,3-galactose, alpha-gal, mammalian meat, or any animal by-products.

Common sources of alpha-gal include:

1. **heart valve replacement** derived from pig or cow,
2. **monoclonal antibodies** (cetuximab)
3. **vaccines** (zostavax, MMR and some flu),
4. **pancreatic enzyme replacement therapy,**
5. **thyroid hormone replacement,**
6. **fillers in medications** (magnesium stearate, stearic acid, lactic acid, glycerin, gelatin, lactose)
7. **antivenom,**
8. **protein powders,**
9. **vaginal capsules**
10. **heparin**

Alpha-gal & co-infections

Ticks that carry alpha-gal are known to carry many other pathogens that can be simultaneously transmitted to humans. It is possible to acquire any of these other tick transmitted diseases and also have alpha-gal syndrome. It is also possible to have AGS alone.



The lone star tick, the primary source of AGS in the U.S., is known to transmit the following diseases: human monocytotropic ehrlichiosis (HME), ehrlichiosis (*Ehrlichia chaffeensis*, *Ehrlichia ewingii*, and *Panola Mountain ehrlichia*), Rocky Mountain spotted fever (RMSF), tularemia (*Francisella tularensis*), Heartland virus, Bourbon virus, Q fever and tick paralysis, as well as *Borrelia lonestari*, which causes Southern tick-associated rash illness “STARI,” an illness similar to Lyme disease.

With alpha-gal recently discovered in blacklegged ticks, we may also begin to see an increase in AGS in patients with Lyme disease, anaplasmosis, babesiosis, ehrlichiosis, relapsing fever borreliosis, Powassan virus disease, and other diseases transmitted by these ticks.

How to prevent alpha-gal syndrome

For now, the best way to avoid getting AGS is to avoid tick bites. This means wearing tick repellent when working, hiking or playing in grassy or wooded areas where ticks are found. Protecting your pets and doing thorough tick checks after being outdoors is helpful.

If you are bitten by a tick, we suggest following these [eight steps](#).



What to do if you have alpha-gal syndrome?

Learning you have an allergy to all mammalian products can be overwhelming. Because this is such a newly discovered condition there are few resources available.

When it comes to making medical decisions, it's important to have a knowledgeable provider who understands the risks versus benefits of certain medications and procedures. Vaccines that contain gelatin are one of the riskier products. However, if you need a rabies shot, for instance, you and your doctor may decide that the benefits outweigh the risks and take the necessary steps to mitigate the adverse effects.

To learn more about the history, symptoms and how to diagnose alpha-gal syndrome listen to this [interview with Dr. Scott Commins](#), of the University of North Carolina.

Additional help can be found at:

- [Tick-Borne Conditions United](#)
- [Alpha-gal Information](#)
- [ZeeMaps](#) shows where Alpha-gal is located throughout the world.
- [Tick-Encounters, tick identification](#)



Other Lyme Disease Co-Infections

Besides the diseases described above, ticks in different geographic areas may be infected with one or more of the following Lyme disease coinfections: Colorado tick fever virus; Mycoplasmas; Powassan encephalitis virus; Q Fever; Rocky Mountain spotted fever (*Rickettsia*); tickborne relapsing fever, other forms of *Borrelia*, and tularemia.

The Tick Chart below gives detailed information about each of these diseases. Just click on the image below to view the chart. We have not yet identified all the diseases that ticks carry and transmit.

Disease/Condition	Pathogen (U.S.)	Vector (U.S.)	Symptoms
Anaplasmosis (Bacteria)	<i>Anaplasma phagocytophilum</i>	Blacklegged tick (<i>I. scapularis</i> , <i>I. pacificus</i>)	Flu-like symptoms (fever, chills, headache, fatigue, pain)
Babesiosis (Parasite)	<i>Babesia microti</i> , <i>Babesia duncani</i> , <i>Babesia divergens</i> , <i>Babesia MO-1</i>	Blacklegged tick (<i>I. scapularis</i> , <i>I. Pacificus</i>), winter tick	Fever, chills, night sweats, fatigue, headache, pain, shortness of breath, "air hunger"

Colorado Tick Fever

Colorado tick fever is caused by a virus carried by Rocky Mountain wood ticks. Symptoms are acute high fever, severe headache, chills, fatigue, and muscle pain.

Mycoplasma

Mycoplasma species have been identified in ticks. Smaller than bacteria, they invade human cells and disrupt the immune system, causing fatigue, musculoskeletal symptoms, and cognitive problems. Mycoplasmas can be treated with antibiotics.

Powassan Virus

Powassan virus causes tick-borne encephalitis. Patients may be asymptomatic or suffer severe neurologic compromise and death. Common symptoms may include fever, headache, vomiting, weakness, confusion, seizures, and memory loss. Long-term neurologic problems may occur. There are no commercial diagnostic tests for the disease, nor is there specific treatment. However, patients may need to be hospitalized to receive care to reduce swelling in the brain or for respiratory support.

Tick Paralysis

Certain ticks secrete a toxin that causes a progressive paralysis, which is reversed when the tick is removed.

Q Fever

Q fever is caused by *Coxiella burnetii*, a kind of bacteria carried by cattle, sheep, and goats. Symptoms are similar to those of Lyme disease. Q fever is likely to start with a high fever. Pneumonia and abnormal liver function also suggest Q fever. Doxycycline is the treatment of choice.

Rocky Mountain Spotted Fever

Rocky Mountain spotted fever is caused by bacteria called *Rickettsia rickettsii* that are transmitted by the bite of a tick. Patients develop high fever, rash, headache and bleeding problems. Thirty percent of untreated patients die. It is treatable with antibiotics, often doxycycline.

Tickborne Relapsing Fever

The agent of tickborne relapsing fever, *Borrelia hermsii*, is carried by soft ticks of the western United States. It is characterized by cycles of high fever and is treated with antibiotics.

Tularemia

Tularemia, or rabbit fever, occurs throughout the United States. It is caused by the bacterium *Francisella tularensis*. Symptoms may include skin ulcers, swollen and painful lymph glands, inflamed eyes, sore throat, mouth sores, pneumonia, diarrhea and vomiting. The most effective treatment is with fluoroquinolones.



Authority on Lyme

“LymeDisease.org’s Member Community is THE one place to refer anyone wanting to get accurate info about Lyme Disease. It’s now more like an authority that people go to other than the CDC. We need to support you in order to keep all the issues regarding this disease relevant in the minds of all. ”

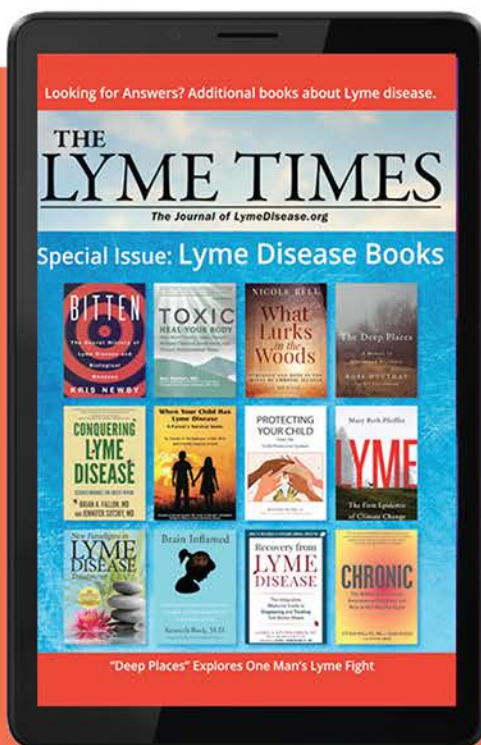
— Patient



Help us advocate for change, raise awareness, and fund research that can improve patient’s lives.



Visit LymeDisease.org
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Lyme Times

The Lyme Times connects you to trustworthy information about critical research, events and treatment for Lyme and other tick-borne diseases.