



Lyme Action Network

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Tick-borne diseases and how to protect yourself

3RD EDITION

This information was produced by the Lyme Action Network with a grant from the South High Marathon Dance - South Glens Falls High School, with further donations from *The Post-Star Newspaper*



Lyme Action Network

WHAT YOU NEED TO KNOW ABOUT TICK-BORNE DISEASES (TBDs)

The Lyme Action Network is a 501(c)(3) not-for-profit organization dedicated to pursuing solutions to help victims of tick-borne diseases.

The Lyme Action Network works at national, state, and local levels with policy-makers, scientists, physicians, and other advocates to improve education, diagnostics, and treatment for people who suffer due to tick-borne diseases. www.LymeActionNetwork.org

Reports from the Centers for Disease Control and Prevention (CDC) and Quest Diagnostics note that the black-legged ticks that carry Lyme disease have been reported in all U.S. States and over half of all U.S. counties. Recorded cases of Lyme disease have expanded, as well, with the annual number of new cases reaching approximately 400,000.

Unfortunately, the CDC's estimates will likely fall short of the actual number of new infections, many of which will not be diagnosed nor reported. Because tick-borne diseases are misunderstood and misdiagnosed at alarming rates, it is critical for people to have a basic understanding of: 1) the various

diseases transmitted by ticks; 2) effective methods of prevention; 3) common symptoms; 4) common misinformation; 5) treatment options and patients' rights.

Borrelia burgdorferi, the causative agent of Lyme disease, is not the only pathogen or disease that ticks transmit. *Babesia*, *Bartonella*, *Ehrlichia*, *Anaplasma*, Powassan virus, *Borrelia miyamotoi*, *Borrelia mayonii*, STARI (transmitted by the Lone star tick), and others have been reported not only in the northeastern United States, but in other sections of the country as well.

Science is at the beginning of the learning curve when it comes to tick-borne diseases. Unlike most

other diseases, we have only a basic understanding of Lyme disease and the way these various diseases, or "co-infections" influence each other when someone is infected. Much more research is necessary, and much better education, diagnostics, and treatments should be national imperatives. In the meantime, YOU need to be informed, as you may well have to make important decisions for yourself or your family.

All information provided by the Lyme Action Network is supported by scientifically-validated research. Contact us at info@LymeActionNetwork.org for more information

PREVENTION TIPS

- Wear light colored clothing so that you can see the ticks.
- Wear long sleeves.
- Spray your outdoor clothing with permethrin, which kills ticks on contact. Never spray it on skin.
- Store permethrin treated clothes in plastic bags in the garage for your next outing.
- Use insect repellent. Spray it on outdoors. Shower and do a tick-check when you come in.
- Tuck pant legs into socks.
- Repellents with at least 20% DEET seem to be the most effective. Use according to directions.
- Natural repellents, like lemongrass and citrus oil, can also be effective, but maybe not as effective as DEET. Reapply every 2-3 hours.
- Do frequent "tick checks" for adults, children, and pets.
- Throw your clothing into the dryer for 15 minutes when coming indoors.

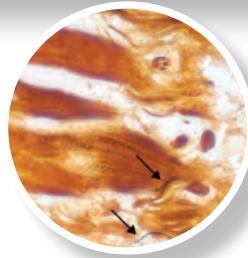
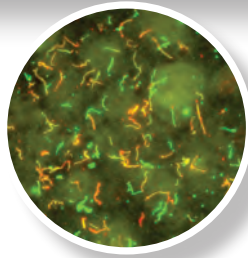
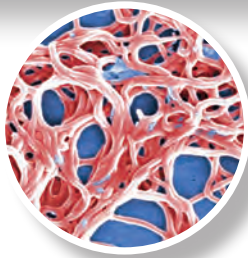
DID YOU KNOW?

Man's best friend can be an unwitting accomplice when it comes to transporting ticks. Ticks can hitch a ride on your pets, which then bring them into your house. People

who allow their pets to sleep in the bed with them often report finding ticks in the bed.



LYME DISEASE - THE BASICS



Lyme disease is caused by a bacteria, *Borrelia burgdorferi*, that is passed to the victim through the bite of an infected tick. The *Borrelia* bacteria is a corkscrew-shaped spirochete that can “drill” into tissue, allowing it to infect any area of the body. The *Borrelia* organism has been shown to have the capacity to change form under certain conditions. It can be a spirochete; it can change into a cyst-form to evade antibiotics. *Borrelia* can alter its cell wall and create multicellular communities called biofilms, which protect them from a wide range of

threats, including antibiotics and the immune system. It has recently been discovered to form “persister” cells, which may contribute to long-term illness. It’s a very “smart” organism. *Borrelia burgdorferi* is a “stealth” pathogen. Unlike other infectious organisms such as strep, which is considered a “frontal” pathogen, stealth pathogens are designed to hide in the body, causing damage wherever they lurk, evading antibiotic and immune system attack. Unlike frontal pathogens, which respond to a short course of antibiotics,

stealth pathogens often require longer, more aggressive therapies. Lyme disease is often characterized by symptoms that migrate. One day you might have pain in your knees, the next day you might have a headache, two days later you have digestive troubles. Lyme disease often -- but not always -- begins with “flu-like” symptoms, including fatigue, joint pain, and headache. If treated rapidly and thoroughly, it can usually be cured. If not treated, it can progress to more serious, long-term illness.

DID YOU KNOW?

You won’t feel a tick bite. The tick anesthetizes the skin as it bites you. It can attach, feed, and detach without you knowing about it. Some ticks are so tiny that you’d never realize they are attached to hard-to-see places like on your scalp or on your back.



PARTIAL LIST OF LYME DISEASE SYMPTOMS

- | | | |
|---|--|---|
| Headache | <i>Twitching of the face or other muscles</i> | <i>Sexual dysfunction or loss of libido</i> |
| <i>Burning or stabbing sensations; shooting pains</i> | <i>Skin hypersensitivity</i> | <i>Mood swings; depression; irritability</i> |
| <i>Joint pain, swelling; stiffness of joints or back</i> | <i>Fatigue, tiredness, poor stamina</i> | <i>Forgetfulness; poor short-term memory</i> |
| <i>Muscle pain or cramps</i> | <i>Unavoidable need to sit or lie down</i> | <i>Difficulty thinking; confusion; poor attention</i> |
| <i>Neck stiffness, pain; neck creaks or cracks</i> | <i>Unexplained fevers, sweats, chills or flushing</i> | <i>Problem absorbing new information</i> |
| <i>Chest pain; rib soreness</i> | <i>Unexplained menstrual irregularity</i> | <i>Difficulty with speech, writing</i> |
| <i>Sore throat; swollen glands</i> | <i>Unexplained weight loss or gain</i> | <i>Difficulty with concentration and reading</i> |
| <i>Upset stomach or abdominal pain</i> | <i>Unexplained hair loss</i> | <i>Difficulty finding words; name blocking</i> |
| <i>Shortness of breath; cough</i> | <i>Eyes: double, blurry, vision loss, floaters, light sensitivity</i> | <i>Disorientation; getting lost, going to wrong places</i> |
| <i>Change in bowel function</i> | <i>Ears: hearing loss; buzzing, ringing, pain, sound sensitivity</i> | <i>Light-headedness; poor balance</i> |
| <i>Bladder dysfunction; irritable bladder</i> | <i>Pulse skips; cardiac impairment</i> | <i>Vertigo, wooziness</i> |
| <i>Testicular pain; pelvic pain</i> | <i>Heart block; heart murmur</i> | <i>Increased motion sickness</i> |
| <i>Unexplained breast pain</i> | <i>Heart palpitations; heart valve prolapse</i> | <i>Exaggerated symptoms or worse hangover from alcohol</i> |
| <i>Unexplained milk production</i> | <i>Sleep: disturbed; too much; too little; frequent or early waking</i> | |
| <i>Numbness; tingling; tremor</i> | | |
| <i>Facial paralysis (Bell’s Palsy)</i> | | |

ABOUT TICKS



The common deer tick (*Ixodes scapularis*) is the primary carrier of the *Borrelia burgdorferi* pathogen. It also carries *Babesia*, *Bartonella*, *Anaplasma* and *Ehrlichia*, *Borrelia miyamotoi*, *Borrelia mayonii*, Powassan virus, and other pathogens. This tick is common to many areas of the country, including the northeast U.S.



The Lone Star Tick (*Amblyomma americanum*) has exploded in the southern region of the U.S., but has recently been recorded in nearly every state in the eastern half of the U.S. and several sites in Canada. In addition to *Borrelia* and other pathogens, this tick can carry a pathogen that causes a Lyme-like disease called STARI. Some people develop an allergy to red meat after being bitten by an infected Lone Star tick.

When the tick attaches to skin, it passes along whatever pathogens it has in its mouth or in its gut, including *Borrelia burgdorferi*, *Babesia*, *Bartonella*, *Anaplasma*, *Ehrlichia*, etc. Any one of these pathogens can result in serious illness. Several diseases passed on through one bite can complicate diagnosis and treatment.

LYME DISEASE - Q&A

Q: How long does it take a tick to transmit disease to a human?

A: Less than 15 minutes! There have been no human studies on the length of time it takes to transmit Lyme disease. Animal studies indicate that transmission can occur in less than a day. Anecdotal reports tell of transmission in less than 4 hours. Other pathogens that cause serious disease can be transmitted rapidly. You are at risk for contracting a disease if the tick is attached for any length of time.

Q: What should I do if I have a tick attached to me?

A: Remove the tick immediately using fine-tipped tweezers, grab the tick where it meets the skin, and pull up. Or use a tool like the O'Tom Tick Twister® to twirl the tick out. These are easy and very effective. DO NOT SQUEEZE THE BODY OF THE TICK, as this can squeeze the contents of the tick into your skin. Do not delay removal.

Q: I've been bitten by a tick. Now what??

A: Find out if the tick carries an organism that can make you sick. Save the tick in a zip-lock bag and send it to the Laboratory of Medical Zoology at the University of Massachusetts (<https://www.tickreport.com/>). This lab will tell you (a) what type of tick it is; (b) whether the tick has been feeding on your blood (engorgement); and (c) if the tick carried *Borrelia*, *Anaplasma*, and/or *Babesia* (you can add other pathogens to the

report for an additional fee). Knowing your risk of exposure to a disease-causing agent following a tick bite can guide the decision of what to do next.

Q: Antibiotic? Or no antibiotic?

A: You need to understand the risks and benefits behind this choice. Download the ILADS Guidelines (www.ilads.org) for the recommendations of this professional medical society (International Lyme and Associated Diseases Society) and discuss with your doctor. There is disagreement over treatment protocols. You will need to specifically ask for the ILADS protocol if that is what you prefer.

Q: Will two pills of doxycycline prevent Lyme disease?

A: There is no scientific evidence to indicate that treating a tick bite with two pills of doxycycline actually prevents Lyme disease. Based upon a single study done 17 years ago that only followed patients 6 weeks and judged them uninfected solely on the presence or absence of a bulls-eye rash, the CDC suggests that a single dose of doxycycline (200 mg or 2 pills) will "prevent" you from developing Lyme disease. However, this treatment does not necessarily prevent the disease - it prevents the symptoms of the erythema migrans ("bull's-eye") rash at the bite site. The recently published, evidence-based, peer-reviewed guidelines issued by the International Lyme and Associated Diseases Society (ILADS)

acknowledge that the one dose approach is not an effective way to prevent Lyme disease.

Q: Watchful waiting?

A: The recognizable symptoms of Lyme disease ("bull's-eye" rash, fever, flu-like symptoms) don't always occur, which can lead to a missed diagnosis. Symptoms of Lyme disease are not predictable (see SYMPTOMS, page 3) and can appear immediately or weeks, months, or years after the bite. Lyme disease gets more difficult to treat the longer you have it. The currently used blood tests that measure antibodies in blood (ELISA and Western blot) are indirect measures of past exposure to the disease-causing agent. These most common tests are not reliable nor accurate, especially early or late in the course of the disease, and are often falsely negative. False positives are very rare. Some states have passed a law requiring physicians to tell patients that a negative blood test result does not mean that you don't have Lyme disease. Until more reliable diagnostic tests are available, Lyme disease should be considered a "clinical diagnosis," meaning, based on signs and symptoms. You may need to stay in contact with your physician about your symptoms so that a "clinical diagnosis" can be made.

Q: Am I safe if I don't get a bulls-eye rash?

A: NO! Only about 30% of people with confirmed Lyme disease report

DID YOU KNOW...

There is interesting research underway:

- **BORRELIA BURGDORFERI, THE CAUSATIVE AGENT OF LYME DISEASE, FORMS DRUG-TOLERANT PERSISTENT CELLS.**

American Society for Microbiology (May 26, 2015) Bijaya Sharma, Autumn V. Brown, Nicole E. Matluck, Linden T. Hu, Kim Lewis

RESEARCH FINDINGS:

- Persisters exist,

- Persisters can be killed with FDA approved drugs,
- Persisters can be killed with pulsed dosing antibiotics

- **SUPPRESSION OF LONG-LIVED HUMORAL IMMUNITY FOLLOWING BORRELIA BURGDORFERI INFECTION PLOS (July 2, 2015)**

Rebecca Eisner, Christine J. Hastey, Kimberly J. Olsen, Nicole Baumgarth

RESEARCH FINDINGS:

- *Borrelia* shuts down antibody production

LYME DISEASE - Q&A

seeing a bulls-eye rash. Some people report seeing some other vague diffused rash, and some people report not seeing any rash at all. You may be infected even if you do not see any rash at all.

Q: Why is Lyme disease called the Great Imitator?

A: As you can see from the list of symptoms (see page 3), Lyme disease can attack any of your body's systems: cardiac, neurological, orthopedic, digestive, muscular, etc., and Lyme symptoms often look like other diseases. Misdiagnosis is very common, and costs the patient valuable time and health while diseases you do not have are unnecessarily treated.

Q: If Lyme is caused by a bacteria, why isn't a week of antibiotics sufficient to cure me?

A: *Borrelia burgdorferi* is a "stealth" pathogen. Unlike other bacteria, like strep, which is a "frontal" pathogen, "stealth" pathogens are built to evade antibiotics. These "stealth" pathogens hide out in areas that get little blood flow, and employ various strategies to protect themselves from antibiotics. These are smart and versatile organisms that require a skillfully administered treatment by knowledgeable doctors.

Q: Are there diagnostic tests to confirm the presence of Lyme disease?

A: Current blood tests (serology) for Lyme disease are notoriously

inaccurate. Serology does not confirm an actual infection, just the presence of antibodies fighting an infection, and cannot be used to evaluate the success of antibiotic treatments. Test results are incorrect 30% to 50% of the time. Serology is currently the type of test that most health care providers rely on to make a diagnosis of Lyme disease.

Other testing options available (including in New York State) that you can bring to the attention of your provider include:

- The Ceres Urine Antigen Test (<http://www.ceresnano.com/nanotrap-lyme-test>), available from Ceres Labs, detects parts of the Lyme disease bacteria in urine and can therefore directly indicate whether you are currently infected.
- IGeneX, Inc. (<http://igenex.com>). Serological testing from this laboratory, which includes both standard tests and now also a new, more inclusive Lyme ImmunoBlot, was approved by the CLEP program of the NYS Department of Health, making these tests available to all qualified New York practitioners and their patients.

These laboratories do not bill insurance directly, so be prepared to pay for the test first and submit the receipt to your insurance company for reimbursement. Appeal the insurance company's rejection should it occur.

Q: Why is there controversy about Lyme disease?

A: In the mid 1970's, when Dr. Allen Steere embarked on the study of an unknown illness in Lyme, CT, he discovered a population suffering with a wide variety of unexplained

symptoms. To be certain that the subjects in his study all had the same disease, he selected for inclusion in his research ONLY those who had a bulls-eye rash. The rash, he reasoned, guaranteed that all subjects had the same disease. In "pre-selecting" his study group, however, Steere excluded patients with Lyme disease who did not have the bulls-eye rash. We now know, "no rash" reflects the experience of the **majority** of Lyme patients. Because of this error in basic research design, all early research was conducted only on one limited segment of the Lyme disease population, to the extreme detriment of patients and overall scientific understanding of the disease. Unfortunately, the Infectious Diseases Society of America (IDSA) and the CDC continue to base their definition of Lyme disease upon the original Steere research. In contrast, the International Lyme and Associated Diseases Society (ILADS) uses current, unbiased research to inform their concept of the disease. Recent research has confirmed the existence of persister cells and other factors that are helping to add dimension to science's understanding of this complex disease. These two professional viewpoints have inspired disagreement on this topic for decades. Interested parties should read the original research and form their own opinions.

Q: Can Lyme be sexually transmitted?

A: There is insufficient research data on this question. It is notable, however, that Lyme disease is the second most prevalent infectious diseases in the U.S. behind Chlamydia (#1), and ahead of Gonorrhea (#3), both STD's. More research is necessary.

MORE ABOUT BLOOD TESTS

The standard testing strategy for Lyme disease involves a series of two tests referred to as "two-tier serology." These tests detect antibodies your immune system produces when you have been exposed to the bacteria that cause Lyme disease, *Borrelia burgdorferi*.

Although the test has two "tiers," a positive result on the first "tier," called an ELISA, is required before the second "tier" test, called a Western blot, is even performed. It's important to know that the ELISA has a sensitivity of only 50%. This means that out of 100 people who actually HAVE Lyme disease, only 50 will show up positive on this test. The other 50% will be told their test was negative and they don't have Lyme disease, EVEN IF THEY DO!

For those that do test positive on the first tier ELISA, the second test called a Western blot is a subjectively interpreted pattern of specific antibodies. The clinical accuracy of this test is also questionable, as it is known that various testing laboratories interpret the results of this test differently. Even people who are positive on the first tier can be negative on the second tier and be told they don't have Lyme disease, EVEN IF THEY DO!

Bottom line – you MAY have Lyme disease, even if you are told your blood test results were negative. Blood test results should only be considered as part of a more comprehensive set of criteria for diagnosis, with the stronger emphasis placed on patient symptoms and outcomes.

COMMON MISDIAGNOSES

Autism
Chronic Fatigue Syndrome
Colitis
Crohn's Disease
Early ALS
Early Alzheimer's Disease
Encephalitis
Fibromyalgia
Fifth's Disease
Gastro-esophageal Reflux Disease

Infectious Arthritis
Interstitial Cystitis
Irritable Bowel Syndrome
Juvenile Arthritis
Lupus
Meniere's Disease
Multiple Sclerosis
Osteoarthritis
Prostatitis
Psoriatic Arthritis

Psychiatric disorders (bipolar, depression, etc.)
Raynaud's Syndrome
Reactive Arthritis
Rheumatoid Arthritis
Scleroderma
Sjogren's Syndrome
Sleep disorders
Thyroid Disease
& Various other illnesses

LYME DISEASE QUICK FACTS

LYME FIGURES UPDATED BY LAN

400,000

CDC reports: Lyme disease infects 400,000 people a year. 10 times more Americans than previously reported.



7,692

CASES PER WEEK

1,096

CASES PER DAY

FASTEST GROWING

As reported by the CDC, there are more new cases of Lyme disease in US annually than Hepatitis, HIV, Colon Cancer, and Breast Cancer

HEPATITIS

17,000

COLON CANCER

136,830

HIV INFECTION

50,000

BREAST CANCER

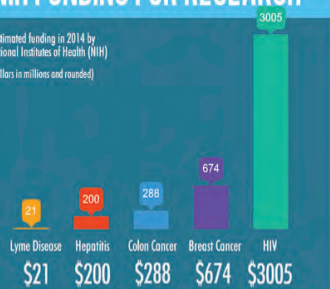
232,570

LYME DISEASE

400,000

NIH FUNDING FOR RESEARCH*

*Estimated funding in 2014 by National Institutes of Health (NIH) (Dollars in millions and rounded)



NO RELIABLE TEST

There is no reliable test to diagnose Lyme disease. The average patient sees 5 doctors over nearly 2 years before being properly diagnosed.

50%

Fewer than 50% of patients with Lyme disease remember a tick bite.

50%

Fewer than 50% of patients with Lyme disease recall any rash.

35%

The common Eritro test you receive at your doctor's office misses 35%-50% of culture proven Lyme disease.

VERY SICK PEOPLE

Some people with Lyme disease are as disabled as people with congestive heart failure, and have as much pain as post-surgery patients.

40%

40% of Lyme patients end up with long term health problems.

40%

Short treatment courses have resulted in upwards of a 40% relapse rate.

60%

60% of patients with untreated infection may have arthritis, with severe joint pain and swelling.

Infographic by Daniel Cameron MD
More at www.danielcameronmd.com/

WHAT ARE THE POLITICS OF LYME DISEASE?

The politics surrounding Lyme disease are frustrating and exceedingly costly to patients. Poor understanding of the biology of the bacteria that cause Lyme disease (*Borrelia*) led to flaws and biases in early medical research. Participants in those early studies were presumed to best represent the clinical disease experienced by the majority of Lyme patients, a presumption that today is known to be false. Subsequent medical guidelines for Lyme disease, developed and supported by the influential Infectious Diseases Society of America (IDSA), are based entirely on these antiquated and flawed original studies. Therefore, the medical community's understanding of the scope and complexities of Lyme disease is very incomplete.

The IDSA contends that: 1) Lyme disease is caused by *Borrelia* that are injected into the skin by the bite of a tick; 2) the vast majority of people who develop Lyme disease will develop a "bull's-eye" rash at the site of the tick bite; 3) for those who don't develop the bulls-eye rash, the IDSA maintains that existing laboratory

tests are accurate for diagnosis; 4) the IDSA rejects the use of additional antibiotic treatment for patients who do not experience a full recovery. **Not one of these assertions holds up to scrutiny when evaluated in the context of the existing scientific and medical evidence.**

The IDSA will not accept that their medical guidelines, based on poorly designed studies done over 30 years ago, apply only to one small subset of Lyme disease patients – specifically, those who develop the bulls-eye rash. It has been repeatedly and reproducibly shown that only 10-40% of Lyme disease patients ever develop any skin rash, and if a rash does develop, it RARELY (<10% of the time) takes the form of a bulls-eye. **Therefore, the predominant medical guidelines that direct how physicians diagnose and treat patients with Lyme disease are based on clinical research**

studies that EXCLUDED 60-90% of people with Lyme disease.

Everyone needs to know that there is more than one approach to diagnosis and treatment of Lyme disease. Physicians are bound by an ethical obligation to discuss ALL available options and to allow the patient (or guardian) to participate in any decision made that pertains to one's care. If your physician is not aware that more than one set of medical guidelines exists, you can print a copy of the evidence-based, peer-reviewed medical guidelines developed by the International Lyme and Associated Diseases Society (ILADS) for them to read. These guidelines were published in a medical journal and also critically reviewed by the National Academy of Medicine and published on the website of the Health and Human Services-sponsored clearinghouse of medical guidelines. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4196523/>



Lyme disease is a complex, poorly understood disease. While there is general agreement that treatment early in the course of the infection can usually cure the disease, there is great debate surrounding later-stage disease. Later-stage disease can be very difficult to address.



There are more and more researchers, scientists, and physicians gathering data and discovering new information about tick-borne diseases. We are in the early stages of understanding the complexities of *Borrelia* infection, and how it relates to other aspects of our biology, such as our immune system.



Unfortunately, the CDC and the Infectious Diseases Society of America (IDSA) base their advice about Lyme disease on outdated data. Many patients are not given up-to-date and accurate information about the disease.



Fortunately, a newer professional medical organization, the International Lyme and Associated Diseases Society (ILADS), offers updated guidance based upon more recent, peer-reviewed data and extensive clinical experience. Medical ethics require that physicians tell patients about ALL treatment options. You have the right to choose the treatment option that you prefer.

DID YOU KNOW?

According to the CDC, Lyme disease requires a clinical diagnosis, not reliance on the blood tests that are highly inaccurate. Your doctor should review your history, your activities, whether you have pets, and all your symptoms to make a determination about a diagnosis. Be sure you ask to be tested for the most common co-infections, as well.

UNDERSTANDING OTHER TICK-BORNE DISEASES

(also called “Co-Infections”)

Q: Are there diseases other than Lyme disease that are passed on through a tick bite?

A: YES! At least a dozen serious pathogens are known to be passed on through tick bites. The most common in this region include: **Babesia** - a malaria-like protozoa that causes serious illness that usually starts with a high fever and chills. As it progresses, the patient may develop anemia, fatigue, headache, drenching sweats, muscle aches, and/or nausea. There are two common strains, *B. duncani* and *B. microti*.

Bartonella - a bacteria that causes illness also known as “cat-scratch fever”. Bartonellosis is characterized initially by fever, fatigue, headache, and an unusual rash that looks like stretch marks or scratch marks. There are several strains of *Bartonella*. **Anaplasma or Ehrlichia** - bacterial infections that cause high fever, fatigue, headaches, and/or muscle aches. Other less frequently seen tick-borne diseases include borreliosis caused by *Borellia miyamotoi*, Powassan virus, Rocky Mountain Spotted Fever (transmitted by dog ticks and Lone Star ticks), tularemia, toxoplasmosis, Bourbon virus, and others. Lone star ticks may transmit a substance (alpha-gal) that causes an allergy to red meat.

Q: If I’m diagnosed with Lyme disease or the co-infections, will my health insurance cover the cost of diagnosis and treatment?

A: Health insurers typically cover blood tests, and one month of IV antibiotics, if necessary. Sometimes they will cover oral antibiotics for a longer period. Since there is disagreement in the medical profession about why Lyme disease symptoms often don’t resolve after

short term treatment, insurance companies might refuse claims for care and treatment that don’t conform to the outdated, rigid IDSA clinical practice guidelines. You should be prepared to appeal the decisions of your insurance company, and you should contact your elected representatives who make the laws regulating the insurance industry.

Q: Do the medicines for one disease also work for the other diseases?

A: While some medications can work for multiple diseases, some of the co-infections require unique medications. It is important that you and your doctor know if you have co-infections. This is particularly true for babesiosis, caused by a malaria-like protozoa that can be mistaken for Lyme disease, or missed in a Lyme diagnosis. Babesiosis is an increasingly common co-infection, but, like Lyme disease, is often overlooked or misdiagnosed.

DID YOU KNOW?

The ILADS Treatment Guidelines are the only clinical practice guidelines for Lyme disease that comply with the Institute of Medicine’s (IOM) Standards for Developing Trustworthy Clinical Practice Guidelines and follow the rigorous GRADE system for rating the quality of evidence and recommendations.

Patients have a right to informed consent, and treatment according to the ILADS guidelines. You can access the guidelines at www.ilads.org

Q: Do the ELISA and Western Blot blood tests also detect co-infections?

A: No, these tests only detect Lyme disease. You must ask your doctor to test you for the co-infections.

DID YOU KNOW?

The Tick-Borne Disease Working Group was established by Congress in 2016 as part of the 21st Century Cures Act to review federal efforts related to all tick-borne diseases. The members of the group, representing balanced subject-matter expertise from all perspectives, are charged to develop recommendations for the federal response to tick-borne disease prevention, treatment and research.

The Working Group is required to submit a report every two years, starting in December 2018. You can learn more about this Working Group at hhs.gov/ash/advisory-committees/tickbornedisease/index.html

DID YOU KNOW?



There is an award-winning documentary about Lyme disease. **Under Our Skin**, directed by Andy Abrahams Wilson, that explores the science, the politics, and the human toll of this disease. The movie can be viewed on Netflix, YouTube, and is available at most libraries. More information can be found at www.underourskin.com

CHILDREN and LYME DISEASE

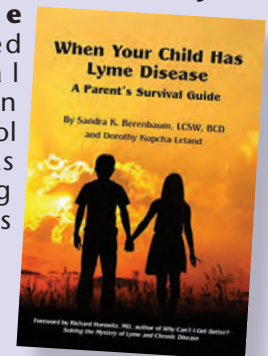
Children ages 5 – 14 are at the greatest risk for tick-borne infections. Symptoms of tick-borne diseases are often described differently by children and teens. Parents, teachers, and caregivers need to be alert for persistent complaints such as stomach aches, bone, muscle or joint pain, tiredness, headaches, vision issues, rashes and fevers. Changes in concentration, behaviors, social activity, and mood should also be noted.

Children may require educational accommodations if they are experiencing learning challenges related to Lyme disease.

Other serious diseases (PANS) can be triggered by Lyme disease. Detailed information can be found at the Children’s Lyme Disease Network (www.childrenslymenetwork.org)



When Your Child Has Lyme Disease has gained national acclaim as an essential tool for parents navigating treacherous waters.



RESOURCES: When Your Child Has Lyme Disease Lyme Literate Press. Berenbaum, S., & Leland, D. (2015). ISBN978-0-996224307 (paperback), ISBN 978-0-99622431-4 (e-book)
Berenbaum-Canon Lyme Disease Screening Protocol. Berenbaum, (2002) . <https://www.lymediseaseassociation.org/images/NewDirectory/Schools/2002-Berenbaum-CanonLD-ScreeningProtocol.pdf>



Lyme Action Network

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RESOURCES

Lyme Action Network - A non-profit organization dedicated to advancements in research, education, and advocacy on behalf of the victims of tick-borne diseases. www.LymeActionNetwork.org

International Lyme and Associated Diseases Society (ILADS) - Professional Medical Society with peer-reviewed Treatment Guidelines. www.ilads.org

Lymedisease.org - International advocacy organization offering guidance on broad spectrum of tick-borne disease issues

Lyme Disease Association - Independent national advocacy organization www.lymediseaseassociation.org

CURE UNKNOWN, by Pamela Weintraub (St. Martin's Press) - Eye-opening account of the politics and corruption preventing advances in Lyme research

WHY CAN'T I GET BETTER, by Richard Horowitz, MD (McMillan) - Detailed explanation of the challenges of tick-borne diseases.

HOW CAN I GET BETTER, by Richard Horowitz, MD (McMillan) - An Action Plan for treating resistant Lyme and chronic disease.

LYME: The First Epidemic of Climate Change, by MaryBeth Pfeiffer (Island Press) - A powerful call to action by an investigative journalist.

SAVE THE TICK! SEND FOR ANALYSIS

TickEncounter Resource Center



If you remove a tick from your skin and would like to have it analyzed for pathogens, place it in a zip-lock bag and send to:
University of Massachusetts - Laboratory of Medical Zoology - www.tickreport.com/

There is a fee for this test.



TICK-BORNE DISEASE NETWORK

Species	Larva	Nymph	Male	Female	Partially Fed Female	Fully Fed Female
Deer Tick <i>Ixodes scapularis</i>						
Dog Tick <i>Dermacentor variabilis</i>						
Lone Star Tick <i>Amblyomma americanum</i>						
Brown Dog Tick <i>Rhipicephalus sanguineus</i>						
Rocky Mountain Wood Tick <i>Dermacentor andersoni</i>					No Image Available	No Image Available
Gulf Coast Tick <i>Amblyomma maculatum</i>					No Image Available	No Image Available

Tick Identification chart reproduced with permission from The University of Rhode Island TickEncounter Resource Center. Chart can be found at www.tickencounter.org/tick_identification

Please help us continue our work! Donate through our web page at www.LymeActionNetwork.org or send to: Lyme Action Network, PO Box 186, Kattskill Bay, NY 12844

THANK YOU!!!