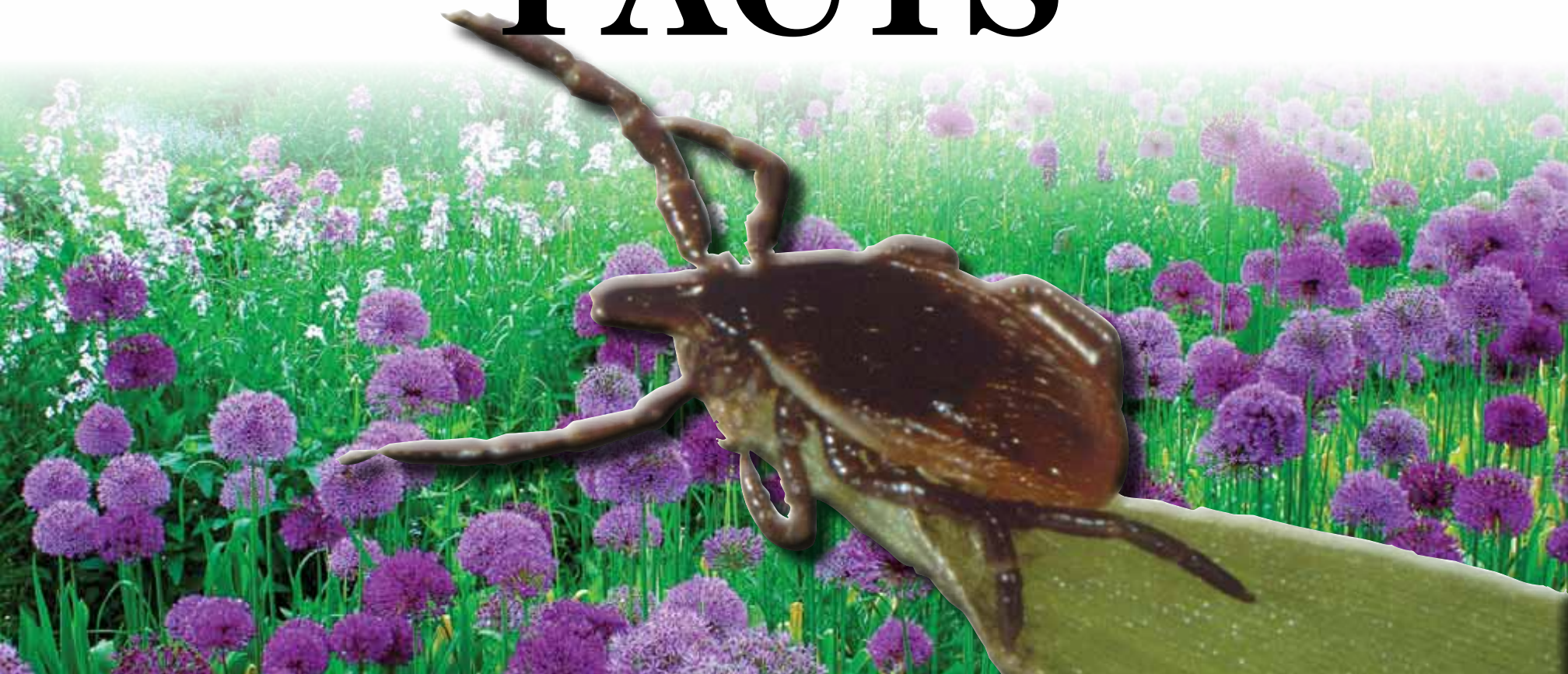




Lyme Action Network

LEARN THE FACTS



Tick-borne diseases and how to protect yourself

This information was produced by the Lyme Action Network through funds from a grant from the South High Marathon Dance - South Glens Falls High School, with further donations from *The Post-Star*, *Saratogian* and *The Chronicle* newspapers.



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.

Living in the northeastern United States carries with it an imperative to be well-informed about tick-borne diseases. The CDC estimates that over 300,000 people a year are infected with Lyme disease, a very high proportion of these cases occurring in the northeastern region of the US.

Unfortunately, it is likely that the CDC's estimates fall short of the actual number. This only underscores how important it is for everyone to have a basic knowledge of: 1) the various diseases that ticks are carrying; 2) reasonable methods of prevention; 3) common symptoms of

tick-borne diseases; and 4) treatment options.

Ticks transmit the pathogens that cause Lyme disease, as well as babesiosis, bartonellosis, ehrlichiosis, anaplasmosis, Powhassan virus, *Borrelia miyamotoi*, and other diseases. All have been found in the northeast United States and in many other sections of the country.

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

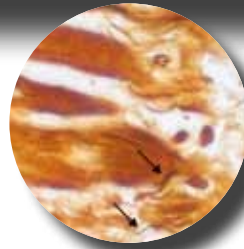
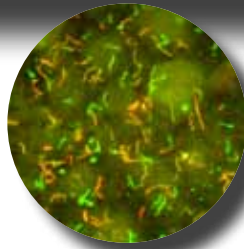
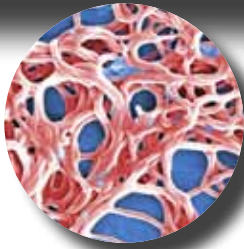
- Wear light colored clothing so that you can see the ticks.
- Wear long sleeves.
- Tuck pant legs into socks.
- Spray your outdoor clothing with permethrin, which kills ticks on contact. Never spray it on skin.
- Store these clothes in plastic bags in the garage for your next outing.
- Use insect repellent. Spray it on outdoors. Wash off when you come in.
- Repellents with at least 20% DEET seem to be the most effective. Use according to directions.
- Natural repellents, like rose geranium oil and citrus oil, can also be effective, but not as effective as DEET.
- Do frequent "tick checks" for adults, children, and pets.
- Throw your clothing into the dryer for 5-10 minutes when coming indoors. Heat kills ticks.

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 coat itself with a protein and become a “cyst-form” to protect itself from the attack of antibiotics; it can alter its cell wall or hide in a biofilm, becoming

invisible to most antibiotics. 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, the stealth pathogens are hard-wired to hide in the body, causing damage wherever they lurk, evading antibiotic 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 rapidly and thoroughly, 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

Burning or stabbing sensations; shooting pains

Joint pain, swelling; stiffness of joints or back

Muscle pain or cramps

Neck stiffness, pain; neck creaks or cracks

Chest pain; rib soreness

Sore throat; swollen glands

Upset stomach or abdominal pain

Shortness of breath; cough

Change in bowel function

Bladder dysfunction; irritable bladder

Testicular pain; pelvic pain

Unexplained breast pain

Unexplained milk production

Numbness; tingling; tremor

Facial paralysis (Bell’s Palsy)

Twitching of the face or other muscles

Skin hypersensitivity

Fatigue, tiredness, poor stamina

Unavoidable need to sit or lie down

Unexplained fevers, sweats, chills or flushing

Unexplained menstrual irregularity

Unexplained weight loss or gain

Unexplained hair loss

Eyes: double, blurry, vision loss, floaters, light sensitivity

Ears: hearing loss; buzzing, ringing, pain, sound sensitivity

Pulse skips; cardiac impairment

Heart block; heart murmur

Heart palpitations; heart valve prolapse

Sleep: disturbed; too much; too little; frequent or early waking

Sexual dysfunction or loss of libido

Mood swings; depression; irritability

Forgetfulness; poor short-term memory

Difficulty thinking; confusion; poor attention

Problem absorbing new information

Difficulty with speech, writing

Difficulty with concentration and reading

Difficulty finding words; name blocking

Disorientation; getting lost, going to wrong places

Light-headedness; poor balance

Vertigo, wooziness

Increased motion sickness

Exaggerated symptoms or worse hangover from alcohol

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*, Powhassan virus, and other pathogens. This tick is common to many areas of the country, including the northeast US.



The Lone Star Tick (*Amblyomma americanum*) is less commonly found, but has been recorded in upstate New York. 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*, the causative agent of Lyme disease, as well as other pathogens (*Babesia*, *Bartonella*, *Anaplasma*, *Ehrlichia*, etc.), often referred to as “co-infections”. Any one of these pathogens can result in serious illness. Several diseases passed on through one bite can complicate diagnosis and treatment.

TICK - Q&A

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

A: 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: Using fine-tipped tweezers, grab the tick where it meets the skin, and pull up. Or use a tool specifically designed to twirl or pry the tick out of your skin, such as an O’Tom Tick Twister®. 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. Remove the tick **immediately**. 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 Tick Report Center 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 can 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 15 years ago, 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 tests are not reliable nor accurate, especially early or late in the course of the disease, and are often falsely negative. 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.

LYME DISEASE - Q&A

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 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: What if I do get a bulls-eye rash?

A: The CDC advises that if you have a bulls-eye rash, you meet the criteria for a confirmed Lyme disease diagnosis. If you have a bulls-eye rash, you have Lyme disease. If you see any rash, bulls-eye or diffuse, the next step would be to see your doctor as soon as possible for antibiotic treatment.

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

A: The blood tests for Lyme disease are notoriously inaccurate. They cannot be relied upon to confirm infection. They return incorrect results from 30% to 50% of the time. If your blood tests do not confirm that you have Lyme disease, your doctor needs to make a clinical diagnosis of Lyme disease based on your symptoms and other factors.

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: Can Lyme disease be passed from mother to fetus in-utero?

A: Yes, evidence indicates that in-utero transmission is possible. Also, spirochetes have been found in infected mothers' breast milk.

MORE ABOUT BLOOD TESTS

The standard testing strategy for Lyme disease involves two tests (a "two-tier" approach). The ELISA is the first tier, and tests for antibodies in the blood indicating exposure to *Borrelia*.

It is important to know that the ELISA test has a sensitivity of LESS than 50%, which means it is WRONG about half the time. If your ELISA test is negative, many doctors will tell you that you don't have Lyme disease. THIS MAY NOT BE ACCURATE. You MAY have Lyme disease, even with a negative ELISA test.

The second test, the Western Blot, is a more complex test that looks for very specific antibodies in the blood.

Different labs interpret the Western Blot results differently, and there is approximately a 70% sensitivity for this test. Again, you MIGHT have Lyme disease even if your Western Blot is interpreted as negative.

COMMON MISDIAGNOSES

Autism
Chronic Fatigue Syndrome
Colitis
Crohn's disease
Early ALS
Early Alzheimers disease
Encephalitis
Fibromyalgia
Fifth's disease

Gastro-esophageal Reflux disease
Infectious Arthritis
Interstitial Cystitis
Irritable Bowel Syndrome
Juvenile Arthritis
Lupus
Ménières Syndrome
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



FASTEST GROWING

As reported by the CDC, these are some new cases of Lyme disease in US annually from Hepatitis, HIV, Colon Cancer, and Breast Cancer.



NIH FUNDING FOR RESEARCH*



NO RELIABLE TEST

There is no reliable test to diagnose Lyme disease. The average patient sees 3 doctors over nearly 2 years before being properly diagnosed.



VERY SICK PEOPLE

Some people with Lyme disease are so disabled that people with congestive heart failure, and have to reach pain in just surgery patients.



WHAT ARE THE POLITICS OF LYME DISEASE?

The politics of Lyme disease are frustrating and exceedingly costly to patients caught in the middle of a raging debate.

Two professional medical organizations, the Infectious Diseases Society of America (IDSA), and the International Lyme and Associated Diseases Society (ILADS), disagree on a number of points relating to Lyme disease, the most significant being whether the *Borrelia* bacteria can persist following treatment with antibiotics.

While mounting evidence indicates that the bacteria can and often does persist, the IDSA refuses to acknowledge this research, and claims that symptoms that persist after limited treatment are not caused by continuing infection, but

rather by other ailments, including possible mental illness. With increasing frequency, patients are being treated for diseases they don't have, or told they have Medically Unexplained Symptoms (MUS), even though the symptoms are consistent with Lyme disease.

The CDC exacerbates the problem. Although the ILADS Treatment Guidelines meet all the requirements for professional treatment guidelines, the CDC, which has the responsibility for the country's health and well-being, has chosen only to represent the much-disputed position of the IDSA in its recommendations, posting a link only to the IDSA Guidelines on the CDC website.

Insurance companies, medical

facilities, and many medical practitioners only follow the outdated guidance of the CDC (IDSA), preventing patients from benefitting from new research, new treatment options, and a better chance to regain their health. Medical ethics dictate that when there are multiple treatment options, as there are for a number of medical conditions, including certain cancers, the patient should be informed of all options, and participate in the process of choosing the best treatment for himself.

This is not happening in Lyme disease. Patients and the general public need to understand the issues, the challenges, and their options, and be prepared to advocate for themselves.

DID YOU KNOW?

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



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 this disease. 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 to right to choose the treatment option that you prefer.

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 *Borellia miyamotoi*; *Powhassan* virus; Rocky Mountain Spotted Fever (transmitted by dog ticks and Lone Star ticks); tularemia; toxoplasmosis; Bourbon virus; and others.

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.

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 older, 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 malarial 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?

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.

DID YOU KNOW?



There is an award-winning documentary about Lyme disease.

Under Our Skin, directed by Andy

Abrahms Wilson, 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

INTERESTING RESEARCH UNDERWAY...

BORRELIA BURGDORFERI, THE CAUSATIVE AGENT OF LYME DISEASE, FORMS DRUG-TOLERANT PERSISTER 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

MORPHOLOGICAL AND BIO-CHEMICAL FEATURES OF BORRELIA BURGDORFERI PLEOMORPHIC FORMS

www.ncbi.nlm.nih.gov/pmc/articles/PMC4339653/

Leena Meriläinen, Anni Herranen, Armin Schwarzbach, Leona Gilbert

RESEARCH FINDINGS:

- Different morphological forms of Borrelia are immunologically distinct.

ADDITIONAL RESEARCH CURRENTLY UNDERWAY:

- New genomic-based diagnostic approaches involving NextGen sequencing and/or detection of specific disease biomarkers such as circulating microRNAs.



Lyme Action Network

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RESOURCES

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

Lyme Action Network - Regional advocacy organization
www.lymeactionnetwork.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 and guidance on how to navigate to solutions by internationally respected clinical expert.

TICK ANALYSIS

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

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, then visit the University of Massachusetts - Tick Report Lab website for more specific instructions:

<https://ag.umass.edu/services/tick-borne-disease-diagnostics>



TICK-BORNE DISEASE NETWORK

Please help us to continue our work on behalf of the victims of tick-borne diseases.

Tax deductible donations may be sent to:

Lyme Action Network, PO Box 186, Kattskill Bay, NY 12844

Thank you!!!