LEARN THE FACTS

Tick-borne diseases and how to protect yourself

www.lymeactionnetwork.org/learnthefacts.pdf

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

A report from the Centers for Disease Control and Prevention notes that the black-legged ticks that carry Lyme disease have been reported in nearly half of all U.S. counties. Recorded cases of Lyme disease have expanded geographically, as well, with new cases projected to reach approximately 400,000 this year. Unfortunately, the CDC’s estimates will likely fall short of the actual number of new infections, many of which will not be diagnosed and 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.

Lyme disease is not the only disease that ticks transmit. *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.

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 maybe 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, 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 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, Borrelia mayonii, 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 commonly found in the southern region of the US, but has recently 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 OTom 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 (“bulls-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 (“bulls-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. 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.

CHILDREN and LYME DISEASE

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.
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.

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.
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, and/or Babesia microti and B. duncani. 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.

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.

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 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.

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 Abrahams 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...


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 BORRELLIA BURGDORFERI INFECTION PLOS (July 2, 2015) Rebecca Eisner, Christine J. Hasty, Kimberly J. Olsen, Nicole Baumgarth

RESEARCH FINDINGS: • Borrelia shuts down antibody production

MORPHOLOGICAL AND BIOCHEMICAL FEATURES OF BORRELLIA BURGDORFERI PLEOMORPHIC FORMS www.ncbi.nlm.nih.gov/pmc/articles/PMC4339653/ Leena Meriläinen, Anni Herranen, Autumn V. Brown, Bijaya Sharma, 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.
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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.

Please help us to continue our work on behalf of the victims of tick-borne diseases. Tax deductible donations may be made through our website at www.LymeActionNetwork.org or sent to: Lyme Action Network, PO Box 186, Kattskill Bay, NY 12844

Thank you!!!