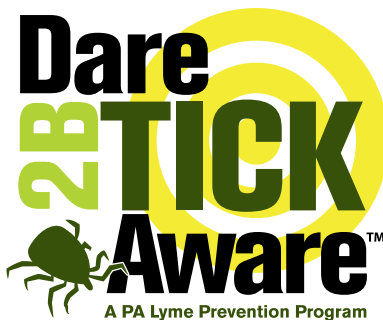


Dare to Know

Recognizing and Treating Lyme & Other Diseases from Ticks



Editorial support and review from
Rita Rhoads Martinez, MPH, CRNP, CNM;
Marina Makous, MD; and
Lee-Ann Gordon, RN, MSN in Public Health Nursing

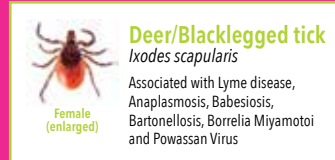


Lyme disease is often a misunderstood illness. It is caused by *Borrelia burgdorferi*, a tiny bacterial corkscrew shaped spirochete. These spirochetes can be passed from an infected tick to humans through a single bite. Ticks also can carry and transmit more than a dozen other serious diseases, called tick-borne diseases or co-infections. The longer an infected tick is attached, the more likely it is to transmit the diseases it is carrying to you.

Ticks can carry and pass Lyme disease and other co-infections to humans through a single bite.

Many Types of Infections Possible

With emerging scientific research, our understanding of tick-borne illnesses is rapidly changing. In Pennsylvania, current research shows that **45% of ticks tested are infected with at least one pathogen, 32% are co-infected with two or more, 9% carry three or more, and 3% of the ticks tested carry four or more infectious agents** (stats updated weekly at www.tickcheck.com/statistics). It's not surprising, then, that people with Lyme disease and other tick-borne diseases experience a wide range of reactions after being bitten by an infected tick.



As new information is discovered, diagnosing and treating these infections continues to change. That is why patients need to educate themselves and become advocates for effective health care.

Dare to Know

This brochure is your guide to the basics of Lyme and other tick-borne diseases. We **"Dare You to Know"** the symptoms, what to expect when you see a health care practitioner, diagnostic dilemmas, treatment options, and your rights as a patient.

Disclaimer: The information in this brochure is for educational purposes only. It is not intended to replace or overrule patient care by a health care provider. If an individual suspects the presence of a tick-borne illness, that individual should consult a health care provider who is familiar with the diagnosis and treatment of tick-borne diseases.



Recognize Early Lyme Signs & Symptoms

Early detection improves treatment success.

MYTH: THERE IS NO RISK OF LYME DISEASE UNLESS YOU GET A BULLS-EYE RASH.

TRUTH: NOT EVERYONE GETS A BULLS-EYE RASH AND THERE CAN BE DIFFERENT KINDS OF RASHES.

SOME EARLY SIGNS AND SYMPTOMS

3 to 30 Days After Tick Bite



Fever and Chills



Headache and Facial Palsy



Fatigue



Muscle and Joint Aches



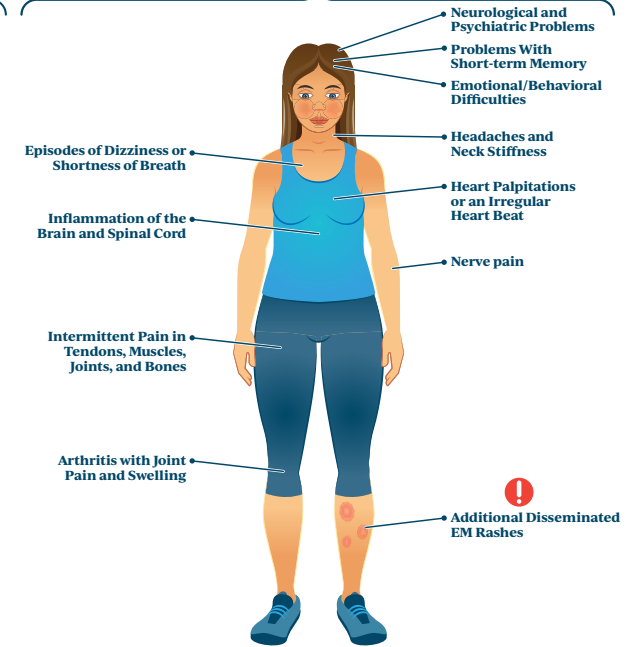
Swollen Lymph nodes



Erythema Migrans (EM) RASH

LATER SIGNS AND SYMPTOMS

Days to Months After Tick Bite



Everyone who lives in Pennsylvania should know how to recognize the early signs of Lyme disease. Our state continuously ranks #1 for the most Lyme cases in the nation. Cases of Lyme have been reported in all 67 state counties, and the geographic range of infected ticks has spread to every region.

Because ticks are small, you may not see a tick on you. Answer these three quick questions to determine your risk:

- **Exposure** - Have you been exposed to a tick habitat? (this could be where you live, camp, hike, ride horses, or play, usually in wooded or grassy areas). The most common place people get tick bites is in their own yard.
- **Tick bite** - Do you recall being bitten by a tick?
- **Rash** - Have you had a red expanding, or unexplained skin rash?
- **Summer flu** - Have you had flu-like symptoms in the summer?

If you think you've been bitten by a tick or have symptoms that could be Lyme disease, see your health care practitioner right away. Every minute counts to stop the spread of the infection. When diagnosed early, Lyme can be more easily treated.

CASE STUDIES

Do any of these stories seem familiar?

CASE STUDY #1 - Teenager pulled off a tick at a summer camping trip. The tick was not sent for testing. Come fall, teen is experiencing headaches and muscle pain.

CASE STUDY #2 - A child has several rashes on her body.

CASE STUDY #3 - A golf player suddenly has a swollen knee and fatigue. He doesn't recall a tick bite, but regularly steps into tall grass to hit a ball out of the "rough."

What to expect when you see your health care practitioner

If you have been bitten by a tick, be sure to call and see a health care practitioner as soon as possible. Ideally, you want a medical professional who understands and has experience treating Lyme and tick-borne diseases. Some may be proactive and prescribe antibiotic treatment for a known tick bite, even if you don't have any symptoms. Others may have you tested and then take a "wait and see approach" for symptoms to appear. If your health care practitioner suggests waiting, track any new symptoms or health issues in a journal and keep them updated as to your condition.

Remember the 50% rule...
less than 50% recall a tick bite, less than 50% recall a rash.

EARLY TREATMENT

Known Tick Bites

The International Lyme and Associated Diseases Society (ILADS) "recommends that known blacklegged tick bites be treated with 20 days of doxycycline..." However, the guidelines go on to recommend longer treatments of specific antibiotics based on the low success rates of 20-day or less treatment trials of EM rashes. See the ILADS Guidelines for complete details at www.ilads.org/patient-care/ilads-treatment-guidelines/

One-Dose Doxycycline... to Take or Not to Take?

While some health care practitioners may prescribe a single dose of doxycycline, ILADS DOES NOT recommend a single dose treatment. It is important to know that the evidence supporting this treatment is weak. Check with your health care practitioner and do your homework on the potential risks and benefits if your physician recommends single dose treatment.



TESTING

When you see your health care practitioner for a tick bite and get tested for Lyme disease, it may come back as "negative." Here's why. The two most common blood tests to detect Lyme: Western Blot and ELISA. Both of these tests DO NOT look for the bacteria itself. Instead, they measure the antibodies that your immune system makes in response to the Lyme bacteria.



After a tick bite, it can take 4-6 weeks for the body to produce measurable levels of antibodies. So, patients who are tested early in a recent infection may test negative, even if they have the classic bulls-eye rash, which indicates the positive presence of Lyme disease. This test result is called a false negative. In the early stages of Lyme infection, many patients will have a false negative Lyme test. Research indicates that, while Lyme testing accuracy is better in later stages, they still miss 50% of actual cases. Test results can produce both false negatives and false positives.

Getting a Diagnosis & Determining Treatment

COMMON MISDIAGNOSES

Lyme is called "the New Great Imitator" as its symptoms often mimic those of many other diseases. Misdiagnoses include: Multiple Sclerosis, Lupus, Rheumatoid Arthritis, Fibromyalgia, Alzheimer's, ADD/ADHD, Parkinson's, Chronic Fatigue Syndrome, depression, anxiety, mental illness, and more.



Diagnosing Lyme disease is very difficult because there is no one test that works well all the time. And the symptoms can range drastically. Practitioners need to piece together your signs and symptoms to determine a diagnosis. So, keeping track of your symptoms, and health changes, after a tick bite is very important to help guide your practitioner.

Consult With Your Healthcare Practitioner If You Have:

- A bulls-eye rash (a positive indication for Lyme in Pennsylvania)
- Any symptoms following a tick bite within 3 to 30 days.
- An enlarging rash and flu-like symptoms, but no known tick bite.
- Symptoms that may be consistent with a tick-borne illness despite a negative Lyme test, and no known tick bite.

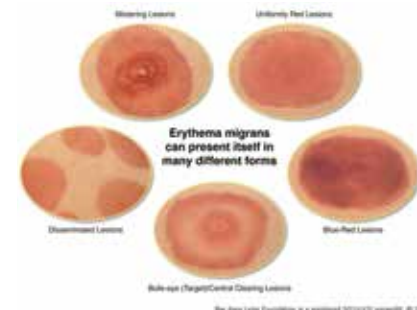
Rashes: In Pennsylvania, a bulls-eye rash means you have Lyme disease and should be treated, no test required. The CDC surveillance definition does not accept the EM rash alone as an indicator in the states it defines as "low incidence" states (<https://ndc.services.cdc.gov/case-definitions/lyme-disease-2017/>). ILADS guidelines indicate that physicians should prescribe 4-6 weeks of antibiotics for a patient with a bulls-eye rash. A rash will not always be a classic bulls-eye; it can look different or there may be multiple rashes, or there may be no rash at all.

GOING UNTREATED

If Lyme goes untreated, it can be harder to successfully treat at a later time. It also can spread to the nervous system and other organs including the brain stem, heart, GI tract, joints and muscles.

When making your decision about treatment, consider these factors:

- Have you had a past tick bite or tick-borne infections?
- Do you have other health conditions?
- Are the symptoms you are experiencing serious?
- What are the risks of treatment versus not treating?



Treatment & Lingerin Symptoms

Feeling Initially Worse

It is important to note that if your health care practitioner prescribes treatment for Lyme or a co-infection, you may initially feel worse before feeling better. This is called a Herxheimer Reaction (or a “herx” for short). The Herxheimer is a temporary worsening of symptoms that occurs when the spirochete is killed off by the antibiotics, creating inflammation.

As the body tries to eliminate (detox) the killed bacteria, it is not uncommon to experience flu-like symptoms including headache, joint and muscle pain, body aches, sore throat, general malaise, sweating, chills, nausea or other symptoms. Share all your experiences with your health care practitioner and consult with them if you have any questions about your treatment, as it is important to distinguish between an adverse drug reaction and a Herxheimer reaction.

You also may feel better initially with treatment, but then get worse again in cycles. This can happen for many reasons. If you stop treatment and symptoms return, consult with your health care practitioner.



Persistent Symptoms: An Evidence-Based Definition

Persistent symptoms in patients treated for Lyme disease are a subject of much debate, and evidence continues to expand and evolve.

*Multiple causes have been identified including: tissue injury, Lyme-induced secondary conditions, unrecognized or undertreated co-infections (e.g. Babesiosis, Bartonellosis, etc.), immune dysfunction of several types, and persistent Lyme infection. Immune dysfunction includes not fully clearing the infection, formation of autoantibodies, persistent activation of immune system.

Experts believe that in persistent cases, likely multiple issues are at play which each need to be addressed for successful treatment (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6963229/>).

If Symptoms Continue

Persistent symptoms are a known issue after short-term treatment in a number of patients. Some practitioners may call it “Post-Treatment Lyme Disease Syndrome.” Recent evidence points to ongoing infection as a cause, but other factors must be evaluated as well (*see box on left). If you continue to have symptoms after treatment, seek the advice of your practitioner. Also, ask them about testing for other diseases that ticks carry. A co-infection, which may not have been addressed in your initial treatment, may be the key to lingering symptoms. Many tick-borne illnesses require treatment with different medicines.

For patients with recurring symptoms, ILADS recommends continuing treatment. “Clinicians should retreat patients who were successfully treated initially but subsequently relapse or have evidence of disease progression... Choices must be individualized and based on several factors, including: the initial response to treatment; the time to relapse or progression; the current disease severity and the level of quality of life impairments.” (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4196523/>)

Emerging Treatment

Research on tick-borne diseases has increased significantly, expanding and refining prior thinking. In rapidly emerging diseases like these, it is critical to stay current in order to self-advocate for the best possible health care options. Stay current through www.palyme.org.

Treatment Options – Two Sets of Guidelines

In emerging diseases, knowledge is developing rapidly and is often uncertain or conflicting. It is common in such situations to have multiple clinical guidelines available to the medical community. Indeed, in Lyme disease, there are two different sets of clinical guidelines published by professional medical societies. Your health care practitioner is required to inform patients of these different guidelines, with the level of evidence supporting them, to guide individualized treatment decision-making.

IDSA Guidelines

Infectious disease doctors typically follow the Infectious Diseases of America (IDSA) guidelines to treat Lyme disease. IDSA guidelines generally require a positive lab test for diagnosis, and provide short-term treatment and no further treatment options for patients who remain ill. With IDSA guidelines, the emphasis on clinical judgment is limited.

ILADS Guidelines

ILADS guidelines provide for clinical judgment and shared medical decision-making based on patient values and preferences. Diagnoses may be made clinically, with lab testing supporting the diagnosis. ILADS guidelines recommend doxycycline for 20 days or longer after a tick bite in an area known for high tick infection. The guidelines also recommend consideration of longer treatment as appropriate, especially when persistent symptoms are present, sometimes with multi-systemic symptoms.

Patients’ Rights

A patient’s right to informed consent and the ability to make an independent decision for themselves are part of the ethical practice of medicine. Shared decision-making is standard in other diseases. Patients are entitled to be informed of alternative thinking and options available for diagnosis and treatment, along with the level of evidence supporting them, in order to make an individualized risk / benefit decision in their care.

Doctor’s Duty to Disclose

In Pennsylvania, Act 83 recommends that health care professionals are required to advise patients that testing may lead to false negatives as well as inform patients about the broad spectrum of scientific views and treatment options regarding all stages of Lyme and related tick-borne illnesses to enable patients to make an informed choice as part of informed consent and to respect the autonomy of that choice. (www.health.pa.gov/)

Additional Resources

Struggling to find a health care practitioner who really understands tick-borne illnesses? Need support from those who have experienced Lyme disease firsthand? Visit www.palyme.org to

- 1) Get referrals for experienced tick-borne disease health care practitioners,
- 2) Find support through one of PA Lyme Resource Network’s regional groups, or
- 3) Download our Dare 2B Tick Aware prevention and awareness literature and other resources.

- ticklab.org – Lab based in East Stroudsburg University, offers free tick-testing to PA residents
- ILADS.org – International Lyme and Associated Diseases Society
- globallymealliance.org – Global Lyme Alliance
- lymediseaseassociation.org – Lyme Disease Association
- lymedisease.org
- projectlyme.org – Project Lyme
- drexel.edu/medicine – Drexel University College of Medicine
- hopkinsrheumatology.org/specialty-clinics/lyme-disease-clinical-research-center/ – Johns Hopkins Lyme Disease Research Center
- columbia-lyme.org – Columbia University Medical Center
- med.stanford.edu/psychiatry/special-initiatives/lyme.html – Stanford Medicine Lyme Disease Working Group
- hhs.gov/ash/advisory-committees/tickbornedisease/reports/index.html – Federal Tick-borne Disease Working Group 2020 Report
- https://cpb-us-w2.wpmucdn.com/blogs.belmont.edu/dist/8/25/files/2020/11/Meland_95-163.pdf – Belmont Law Review, “They Shall Not Be Left to Rot: The Emerging Law of Lyme Disease”

PA Lyme Resource Network offers a collection of Dare 2B Tick Aware™ Lyme prevention and awareness literature.

- Tick Identification card
- PA Lyme Protection Tips card
- Dare to Prevent brochure (personal prevention)
- Dare to Prevent: Pet Prevention brochure
- Dare to Prevent: Yard Prevention brochure
- Dare to Act brochure (tick checks, what to do if you find a tick on you)
- Dare to Know brochure (early recognition of symptoms)
- Dare to Know More brochure (when symptoms persist, coming soon)



To learn more about prevention measures,
visit our website or social media pages.

www.palyme.org

 PA Lyme Resource Network

 @PALyme1

PA Lyme Resource Network (www.palyme.org) is an all-volunteer 501(c)(3) non-profit organization that provides awareness, education, support, advocacy and resources to navigate Lyme and Tick-Borne Diseases in the state of Pennsylvania. PA Lyme was founded in 2012 by individuals with personal experience with these diseases and provides educational seminars, speakers, patient networking and research updates serving the general public, medical professionals, schools, private businesses and government entities. PA Lyme has the largest network of regionally based support groups in the state. The support groups hold local meetings and events to provide support, education and resources for their local communities.

This brochure was funded by a grant from the Lyme Disease Association, Inc.