# Lyme Disease Q&A

For Healthcare Providers in Pennsylvania



### Why is this important?

Pennsylvania is endemic for Lyme disease (LD). *Borrelia burgdorferi*, the bacteria that causes LD, is carried by the *Ixodes scapularis* tick (deer tick, black-legged tick). *I. scapularis* ticks are found in every county of Pennsylvania, even urban counties. Pennsylvanians are considered high risk for LD.

### **Tick Information**

#### How common are ticks in Pennsylvania?

Very common! Ticks carrying the bacteria that causes LD are present in every county in Pennsylvania, including in green spaces in Philadelphia and Pittsburgh and other Pennsylvania cities.

#### Can any tick transmit LD?

No. In Pennsylvania, only the *lxodes scapularis* or deer tick (also called the black-legged tick) can transmit LD. Deer ticks are the most common tick in Pennsylvania.

#### How likely is it that any tick is carrying Borrelia burgdorferi, the bacteria that causes LD?

According to surveillance studies conducted by the Pennsylvania Department of Environmental Protection (DEP), nymphal ticks, which are out in Pennsylvania from late May to late July, have a 1 in 4 chance of being infected with *B. burgdorferi*. Adult ticks, out from late September to May of the following year have a 1 in 2 chance of being infected with *B. burgdorferi*.

#### If a patient is bitten by an infected tick, how likely is it that it will cause LD?

This depends on how long the tick was attached. The tick must be attached for at least 24 hours to begin transmitting LD and in most cases, it must be attached for 36 to 48 hours. If a patient can be sure the tick was only attached for a short period of time, there is no risk of LD. However, other tickborne diseases may require shorter attachment times.

### Epidemiology

#### Is Lyme disease common in Pennsylvania?

Yes! Pennsylvania reports more LD cases than any other state. Per capita, Pennsylvania is usually third or fourth in the country. It is known that LD is significantly underreported. While approximately 10,000 LD cases are reported to the Pennsylvania Department of Health (PA DOH) every year, the true incidence is likely several fold higher.

#### Who is most at risk for LD?

Everyone in Pennsylvania is considered at risk for LD, even people who live in urban areas who may spend time in green spaces. Higher risk is associated with people who spend a lot of time outdoors, especially doing yard work and gardening. Hiking, camping, fishing on banks of rivers, streams and lakes, hunting, and outdoor sports can also be risk factors. People who own dogs are at a higher risk that those who own cats or don't have any pets at all.

The age group that carries the highest risk is children ages 5 to 14. Children play outdoors and may be less likely to take precautions against ticks. Older, retirement age adults also have a



high incidence of LD. It is not clear if they are at a higher risk due to activities or if this higher incidence is reflective of an exacerbation of symptoms in their age group.

#### What time of year is riskiest for LD?

Ticks may be out all year, including in the winter if it's above freezing. Ticks do not die over the winter. However, the riskiest time for LD is the late spring and early summer. This is likely due to a couple of factors. People tend to spend more time outdoors in the warm months of May through August. This is also when nymphal deer ticks are prevalent in the environment. Nymphal ticks are very tiny, the size of a poppy seed, and can be very difficult to see if one does not do careful tick checks. Although the risk of LD exists all year long, half of all Pennsylvania LD cases report symptom onset in June and July.

### **Treating Tick Bites**

# A patient calls or presents to the office with a tick bite, what is the recommended treatment?

If the patient has not already done so, the tick should be removed as soon as possible. The tick should be grasped as close to the skin as possible with tweezers or a tick removal tool and should then be pulled straight up. Resistance may be encountered. Once the tick has been removed, the tick should be killed by placing it in tape or plastic bag to suffocate it. The area should then be cleansed with soap and water.

Advise against old wives' tales such as covering the tick with petroleum jelly, butter or using a match near the tick. These may cause harm to the person and it may cause the tick to be stressed and to regurgitate the contents of its stomach into the host.

A local reaction to the tick bite may occur. This may look like a mosquito bite with some discoloration and possibly some slight swelling. It may also itch. This is not a sign of LD.

#### My patient has the tick, should it be tested?

Tick testing is not recommended by the PA DOH and CDC for clinical purposes for the following reasons. Patients may pursue tick testing for informational purposes.

#### **Timeliness**

Persons who submit ticks for testing may not get the results before they begin experiencing symptoms of a tickborne disease. Diagnosis and treatment should never be delayed while waiting for tick testing results. This is especially true of Rocky Mountain spotted fever (RMSF), a disease transmitted by dog ticks in Pennsylvania. RMSF can have severe outcomes, including death, if treatment is not begun quickly.

#### Negative results

Negative tick testing results do not mean a pathogen has not been transmitted by another tick the person did not find. Studies have shown generally less than 1 in 5 LD cases recalled being bitten by a tick. A currently unpublished study by PA DOH found that only 17% of LD cases in Pennsylvania recalled a tick bite prior to onset of symptoms.

Positive results



Positive tick testing results do not mean a pathogen has been transmitted. Studies have shown deer ticks must be attached for at least 24 hours, and usually 36 to 48 hours, before *Borrelia burgdorferi* is transmitted.

#### Accuracy

Labs that conduct tick testing are not subject to the same regulations as labs which test human specimens, therefore, results may not be as accurate as human lab results.

#### How could tick testing affect patients?

Positive tick testing results in patients who did not have a long tick attachment time could result in the unnecessary use of antibiotics. Overuse of antibiotics may have negative consequences for the patient and for society.

Negative tick testing results in patients who were bitten by another infected tick may result in the patient ignoring tickborne disease symptoms and assuming they had the flu or some other illness. It may also result in the HCP delaying diagnosis and treatment for a tickborne disease, incorrectly believing the patient was not infected due to the negative tick testing results.

# What are my options for treating patients who have been bitten by a tick or have tick testing results?

PA DOH recommends treating patients based on their symptoms and human lab testing results only. Tick testing may be used for research but should not be used to make a clinical diagnosis.

#### Lyme Disease Post Exposure Prophylaxis (PEP) Option

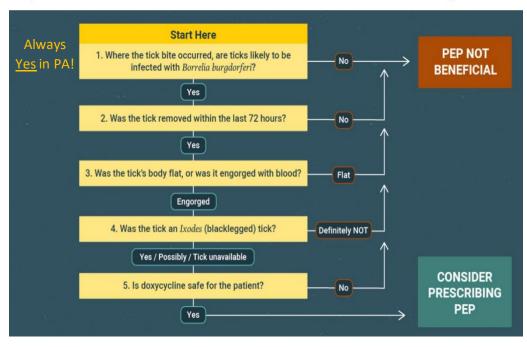
One dose of doxycycline may be given to patients presenting with a deer tick (*Ixodes scapularis* tick) bite that has been attached for at least 36 hours and they present within 72 hours in an area where deer ticks are likely to be infected with *Borrelia burgdorferi*. Every county in Pennsylvania is considered endemic for LD and deer ticks have a high likelihood of being infected in every county. Studies have shown this prophylactic dose may be effective at preventing LD from developing.

Adults: 1 dose (200 mg) who are not pregnant

Children: 1 dose (4 mg/kg up to a maximum dose of 200 mg)



# Lyme Disease PEP: Clinical Decision-Making Aid



# Diagnosis

#### What is a Lyme rash?

The most distinctive sign of LD is an erythema migrans (EM) rash. This is a rash that initially appears at the site of the tick bite. As the disease progresses, the patient may develop multiple EM rashes anywhere on the body. The rash may be red, pink, blueish or purplish on fair and lighter colored skin. On dark skin, it may appear dark red, brown, black or even white. Although often described as a "bull's eye" this is not a common appearance of EM. EM may have just one ring, may be a solid discoloration to the skin, may be round or oval. It may grow to approximately 12 inches across. EM rarely hurts or itches, although that is possible. For a variety of images of EM presentations, click here.

About 70-80% of LD cases have some form of an EM rash.

<u>EM rash is diagnostic for LD</u>. If a patient presents with EM rash in an endemic state like Pennsylvania, treatment may be begun immediately without testing.

#### What are the other symptoms of LD?

Early in the course of LD, symptoms are non-specific and may resemble the flu. Since most LD cases are in the late spring and summer months, when flu is not circulating, a healthcare provider should have a high index of suspicion for LD in patients presenting with flu-like symptoms in the late spring and summer months. The table below shows the symptoms associated with each stage of LD.



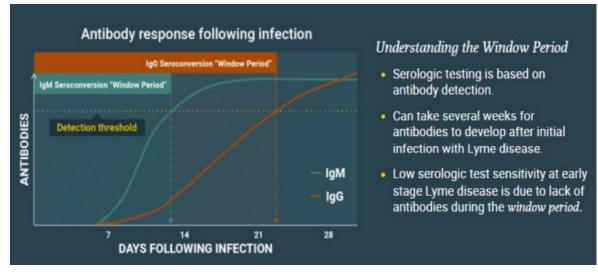
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		3.9	Stages of Lyme Disease
Early Lyme Disease	Within One Month	Erythema Migrans	70 to 80 percent of cases Begins at site of tick bite 3-30 days after bite (average is 7 days) Expands gradually over a period of days up to ~12 inches May feel warm, but rarely itchy or painful Sometimes center may clear resulting in target or bull's eye appearance
		Systemic	Fever, chills, fatigue, headache, joint and muscle aches, swollen lymph nodes
Early Disseminated Lyme Disease	One to Three Months	Cutaneous	Multiple EM rashes
		Neurological	Facial (Bell's) palsey Severe heahaches and neck stiffness (meningitis) Radiculopathy
		Cardiac	Heart palpitations or irregular heart beat Dizziness or shortness of breath
Late Lyme Disease	Three to Many Months	Neurological	Nerve pain Shooting pains, numbness, or tingling in the hands or feet Problems with short-term memory
		Arthritis	Arthritis with severe joint pain and swelling, particularly the knees and other large joints

#### Should I test my patient for LD who just removed an attached tick?

Testing immediately after the removal of a tick will almost always be negative for LD (a positive result likely indicates a prior infection), so testing should be delayed until a patient has symptoms which cannot immediately be identified as LD.

The following charts show the IgM and IgG antibody response windows following infection with LD.



#### Should I test any patient I suspect of having LD?

Not necessarily. As already stated, in patients presenting with EM rash, an immediate diagnosis of LD may be made. Testing is not recommended and may not be helpful in making the diagnosis.

Since most LD testing relies on the production of antibodies to *B. burgdorferi*, testing in the earliest stages of disease may produce false negative results. Therefore, diagnosis and treatment may begin with the presence of an EM rash; testing may be negative in this stage of



disease. It may take up to 4 to 6 weeks after the tick bite for LD test results to appear positive. The following table shows the likelihood that a person with LD will test positive for LD at each stage of disease.

Lyme Disease Stage	Sensitivity (%)
Early acute (EM rash)	46.3
Early convalescent	58.2
Early disseminated (neurologic and cardiac)	89.7
Late stage (neurologic/arthritis)	99.4

Specificity is found to be >95% in all stages.

Testing is strongly encouraged if a person presents with later stage symptoms. If a patient initially tests negative, but symptoms persist and an alternate diagnosis has not been made, retesting is recommended.

#### What are the testing options for LD?

#### Antibody Testing

Serological testing is the most commonly used testing method for LD. For persons presenting with compatible symptoms, the following tests may be conducted.

- 1. Standard two-tier test (STTT)
  - a. The first tier is a serum antibody test and may be an enzyme immunoassay (EIA) or immunofluorescence assay (IFA) for IgM and/or IgG.
  - b. If the EIA/IFA is positive, this will reflex to a Western immunoblot. If this is positive, the STTT is considered positive.
- 2. Modified two-tier test (MTTT)
  - a. Recently approved MTTTs will run two EIA tests concurrently or sequentially. A positive result on both is considered a positive test result.
  - b. The FDA has approved some MTTT testing platforms at commercial labs.

Antibodies normally persist in the blood for months or even years after the infection is gone; therefore, the test cannot be used to determine if a person no longer has LD. Regular IgG immunoblot testing in persons who have previously been cases to attempt to test for cure is not recommended.

#### <u>Culture</u>

Less commonly, *B. burgdorferi* may be isolated in culture, however, this may not yield positive results in persons who have LD as *B. burgdorferi* is difficult to isolate in culture.

#### NAAT Testing

A group-specific NAAT test may also be conducted, however, this has been shown to be less useful for LD caused by *B. burgdorferi* (the predominant cause in Pennsylvania) and more



useful in LD caused by *B. mayonii* (the establishment of *B. mayonii* has yet to be documented in Pennsylvania).

#### Immunohistochemical Assay

In cases in which biopsy or autopsy tissue is obtained, immunohistochemical assays to detect *B. burgdorferi* group-specific antigens may be conducted.

Laboratory Tests that are Not Recommended

- Capture assays for antigens in urine
- Culture, immunofluorescence staining, or cell sorting of cell wall-deficient or cystic forms of *B. burgdorferi*
- Lymphocyte transformation tests
- Quantitative CD57 lymphocyte assays
- "Reverse Western blots"
- In-house criteria for interpretation of immunoblots
- Measurements of antibodies in joint fluid (synovial fluid)
- IgM or IgG tests without a previous ELISA/EIA/IFA

For further information on LD testing and the interpretation of test results, please see <u>APHL</u> <u>Guidance and Interpretation of Lyme Disease and Serologic Test Results</u> (PDF, 17 pages).

#### Is an annual screening for LD recommended?

No, screening for LD is not recommended. If a person is not exhibiting symptoms of LD, there is no reason to test them. If a person is exhibiting symptoms, testing and treatment should not be delayed until an annual screening. Persons who have had LD in the past may continue to have detectable IgG antibodies, i.e., test positive, for months or years after the infection. This is not diagnostic in a person who does not have symptoms.

# If a person has had LD in the past and they are having symptoms again, how do I know if the positive IgG is from the first infection or if this is a new infection?

Unfortunately, since LD testing relies on antibodies which can persist for some time, there is no way to know from testing IgG antibodies if this is a new infection or if the positive IgG is from the prior infection. Some things that may indicate this is a new infection include a positive IgM on a standard or multitier test or an EM rash. If an EM rash is present, this should always be diagnosed and treated as a new infection. If neither of those are present, you will have to use your best clinical judgment. Is the patient experiencing only flu-like symptoms? Have you ruled out other causes like flu, COVID19, other viruses? Is the person experiencing new onset joint pain and/or swelling or other later stage LD symptoms? This could point to a new LD infection.

## Treatment

If I have a patient who tests positive for LD or has EM, what is the best treatment?



LD treatment is based on the patient's clinical manifestations. LD treatment guidance was updated in 2020 and published in <u>*Clinical Infectious Diseases* on January 1, 2021</u>. Summary tables can be found below, one for adults, one for children.

#### LD Treatment Recommendations for Adults

Manifestation	Antibtioic	Duration
	Doxycycline, 100 mg orally twice daily or 200 mg once	11111242
Fatherine missons	daily	10 d
Erythema migrans	Amoxicillin, 500 mg orally 3 times daily	14 d
	Cefuroxime axetil, 500 mg orally twice daily	14 d
Erythema migrans in a patient unable to take beta-		
lactams or tetracyclines	Azithromycin, 500 mg orally once daily	7 d (range: 5-10 d)
Lyme meningitis or radiculopathy		
Ambulatan	Doxycycline, 100 mg orally twice daily or 200 mg once	
Ambulatory	daily	14-21 d
Hospitalized	Ceftriaxone, 2 g intravenously once daily	14-21 d
	Doxycycline, 100 mg orally twice daily or 200 mg once	
Lyme cranial nerve palsy	daily	14-21 d
Lyme cranial neuropathy or radiculopathy in a	Amoxicillin, 500 mg orally 3 times daily	
patient unable to take tetracyclines		14 d
	Cefuroxime axetil, 500 mg orally twice daily	14 d
Cardiac Lyme disease		
Ambulatory	Same as for erythema mirgrans	14-21 d
	Ceftriaxone, 2 g intravenously once daily until stabilized	
Hospitalized	or discharged	
hospitalized	Complete course with oral antibiotic recommended for	
	erythema migrans	14-21 d
Lyme arthritis		
	Doxycycline, 100 mg orally twice daily	28 d
Initial	Amoxicillin, 500 mg orally 3 times daily	28 d
	Cefuroxime axetil, 500 mg orally twice daily	28 d
Pocurrent or refractory arthritic	Re-treat using 1 of the above oral regimens	28 d
Recurrent or refractory arthritis	Ceftriaxone, 2 g intravenously once daily	14-28 d



#### LD Treatment Recommendations for Children

Manifestation	Antibtioic	Duration
	Amoxicillin, 50 mg/kg orally 3 times daily	14 d
Erythema migrans	Doxycycline, 4.4 mg/kg orally twice daily	10-14 d
	Cefuroxime axetil, 30 mg/kg orally twice daily	14 d
Isolated facial palsy	Doxycycline, 4.4 mg/kg orally twice daily	14 d
	Amoxicillin, 50 mg/kg orally 3 times daily	28 d
Arthritis	Doxycycline, 4.4 mg/kg orally twice daily	28 d
	Cefuroxime axetil, 30 mg/kg orally twice daily	28 d
Persistent arthritis after	Retreat with arthritis treatment	28 d
first course of therapy	Ceftriaxone sodium, 50-75 mg/kg, IV, once a day	14-28 d
Atrioventricular heart blo	ock or carditis	
Ambulatory	Same as for erythema mirgrans	14 d (range: 14-21 d)
	Ceftriaxone sodium, 50-75 mg/kg, IV, once a day	de la del de la compositiva de la del del de la del
Hospitalized	Complete course with oral antibiotic recommended for	
	erythema migrans	14 d (range: 14-21 d)
Lyme meningitis		
Ambulatory	Ambulatory Doxycycline, 4.4 mg/kg orally divided into 1 or 2 doses	
Hospitalized	Ceftriaxone sodium, 50-75 mg/kg, IV, once a day	14 d

# Is it preferable to treat children with amoxicillin than doxycycline to not damage their teeth?

Studies have shown that short courses of doxycycline are safe and effective for children and do not result in tooth staining or damage to the tooth enamel.

#### My patient is still testing positive for LD after months, should I re-treat?

No. Antibodies to a pathogen may be present for months or years after infection and is not indicative of continued infection, therefore, additional treatment is not necessary.

# My patient states they still do not feel well even after an appropriate course of antibiotics, should I continue to treat them with more antibiotics?

Additional antibiotic therapy is not recommended for patients who have persistent or recurring nonspecific symptoms such as fatigue, pain or cognitive impairment following recommended treatment for LD, and who lack objective evidence of reinfection or treatment failure (i.e. objective signs of disease activity, such as arthriitis, meningitis, or neuropathy). Some people with Lyme disease, approximately 1 in 5 according to some studies, may continue to experience symptoms or not feel well after they have completed an appropriate course of antibiotics for LD. This is known as Post-Treatment Lyme Disease Syndrome (PTLDS). PTLDS is not well understood at this time, but theories as to why this occurs include lingering damage to tissues and organs due to *B. burgdorferi* infection, an autoimmune response to the infection, a persistent but difficult to detect infection, or some cause unrelated to LD. However, in placebo trials, additional antibiotics have not been shown to help persons with PTLDS and there are risks associated with long term antibiotic use. There is no known treatment for PTLDS at this time.



Patients with PTLDS have been shown to improve over the course of months or possibly years. Avoiding harms due to unnecessary antibiotic exposure or to unnecessary intravenous access devices, supportive treatment and management of symptoms in persons with PTLDS are the recommended courses of action.

## **Follow Up and Prevention**

#### Can a person get LD more than once?

Yes. An infection does not confer lifelong immunity. Reinfection may occur.

#### What is the best way to prevent LD?

The best way to prevent LD is to prevent tick bites. The following strategies are recommended for preventing tick bites.

#### Permethrin

Permethrin is an insecticide that can be applied to shoes, clothing and gear and kills ticks on contact. PA DOH recommends applying permethrin to shoes and clothes that you will be wearing outside to garden, do yard work or to engage in other outdoor activities. You may also purchase pretreated clothing. Permethrin can be found at department stores like WalMart and Target and sporting goods stores like Dick's and Bass Pro Shop as well as online.

#### Insect Repellent

PA DOH recommends using an EPA approved insect repellent when spending time outdoors. Products containing DEET, picaridin or oil of lemon eucalyptus are all effective at preventing tick bites.

#### **Tick Checks**

We recommend conducting tick checks regularly when spending time outdoors. Once inside, conduct a thorough tick check. Small children and older adults may need help with tick checks. A shower is also recommended to remove any ticks that may be crawling on skin and not yet attached.

#### Pet Tick Prevention

Discuss tick prevention for pets with the pets' veterinarians. Dogs can become ill with LD and any pets that spend time outdoors may bring ticks into their homes on their fur. While there are no known instances of cats being infected with LD outside a laboratory, cats can still become ill from other tickborne diseases. Cat owners should be sure to use tick prevention products specifically labeled for cats.

#### Preventing Ticks in the Yard

Recommend keeping grass short and neat, tidying wood piles and moving them to the edges of the yard, trimming shrubs and cutting tall grasses and weeds, and placing mulch borders between the woods and the lawn.

#### **More Information**



For more information on vectorborne diseases and educational materials, please visit the Pennsylvania Department of Health Vectorborne Disease website.



https://www.health.pa.gov/topics/disease/Vectorborne %20Diseases/Pages/Vectorborne%20Diseases.aspx



www.health.pa.gov