

Lyme Disease

Surveillance Protocol

Lyme disease was first recognized in the United States in 1977, after an unusual outbreak of arthritis among children near Lyme, Connecticut¹. It is the most commonly reported vector-borne disease in the United States. Public health surveillance for Lyme disease initiated in 1980, and was nationally notifiable beginning in 1991¹.

Provider Responsibilities

1. Report suspect and confirmed cases of Lyme disease (including copies of lab results) to the local health department within one week of diagnosis.
2. Follow national guidelines for Lyme disease testing^{2,3,4}. Appropriate Lyme disease testing should include a two-tier testing approach that includes an EIA or IFA screening with Western blot confirmation. Laboratories that cannot offer testing can refer specimens directly to the Office of Laboratory Services (OLS) free-of-charge. For questions, contact OLS at 304-558-3530 extension 2410.
 - a. For more information from OLS on Lyme disease testing click [here](#)
 - b. For an OLS Lyme disease specimen submission form click [here](#)

Laboratory Responsibilities

1. Report positive laboratory results for Lyme disease to the local health department within 1 week.
2. Follow national guidelines for Lyme disease testing^{2,3,4}. Appropriate Lyme disease testing should include a two-tier testing approach that includes an EIA or IFA screening of blood or CSF with Western blot confirmation. Laboratories that cannot offer testing can refer specimens directly to the Office of Laboratory Services (OLS) free-of-charge. For questions, contact OLS at 304-558-3530 extension 2410.
 - a. For more information from OLS on Lyme disease testing click [here](#)
 - b. For an OLS Lyme disease specimen submission form click [here](#)

Public Health Action

1. Conduct an appropriate case investigation. For each case,
 - a. Contact the physician that either reported the case or ordered Lyme disease testing
 - b. Using “Form A” from the Lyme disease case investigation toolkit (see [Appendix A](#) of this document), collect the clinical information necessary to

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perform case ascertainment. Local forms may be used, as long as the same information is collected. A provider “quick sheet” on Lyme disease has been developed (also in [Appendix A](#)), and may accompany “Form A” if faxed or mailed.

- c. To determine relevant exposure information, contact the patient if they had a physician-diagnosed erythema migrans measuring 5cm or greater. Patients without EM do not need to be contacted.
 - d. For patients with EM, use “Form B” from the Lyme disease case investigation toolkit (see [Appendix A](#) of this document) to collect the information about exposure. Local forms may be used, as long as the same information is collected.
 - e. Educate the patient and the patient’s family on Lyme disease prevention; reinfection is possible and has been documented⁵.
 - f. Report all case data using WVEDSS.
2. Educate the public about Lyme disease, especially regarding the mode of tick transmission and use of personal protection. Cases of Lyme disease usually occur between April and November in West Virginia and there is an endemic focus of Lyme disease in the eastern panhandle; increased public education should be targeted toward this time frame and location, with the understanding that Lyme disease may be reported year-round. Additionally, the eastern panhandle of West Virginia borders sections of 3 states (Maryland, northern Virginia, and southeastern Pennsylvania) that have considerable Lyme disease activity⁶.
 3. Educate providers and laboratories to report cases of Lyme disease to the local health department in the patient’s county of residence within one week of diagnosis.
 4. Educate providers and laboratories about appropriate laboratory confirmation of Lyme disease using the recommended two-tiered testing approach (EIA/IFA screening of blood or CSF with Western blot confirmation).

Disease Control Objectives

1. Increase the number of patients treated with antibiotics in the early stages of Lyme disease to reduce number of patients with disseminated and late disease.

Disease Prevention Objectives

1. Reduce disease risk through public education by encouraging use of personal protective measures.

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Disease Surveillance Objectives

1. To identify and monitor the epidemiologic characteristics (including demographics and risk factors) of Lyme disease in West Virginia.
2. To identify areas endemic for Lyme disease in West Virginia.
3. To monitor laboratory testing practices by physicians diagnosing Lyme disease in West Virginia residents.

Public Health Significance

Lyme disease is transmitted to humans by the bite of infected deer ticks⁷. In the United States, endemic foci of Lyme disease exist along the Atlantic coast and are concentrated between Massachusetts and Maryland; in the upper midwest, an expanding focus is currently concentrated in Wisconsin and Minnesota; and in some areas of California and Oregon. Lyme disease continues to increase nationally. State health departments reported 28,921 confirmed cases of Lyme disease to CDC in 2008, compared with just over 15,000 confirmed cases in 1999⁶.

Initial infection occurs primarily during summer, with peak in June and July, but may occur throughout the year, depending on the seasonal abundance of the tick in different geographic areas⁷. The distribution of most cases coincides with the distribution of *Ixodes scapularis* (formerly called *I. dammini*) ticks in the eastern and midwestern United States. The explosive repopulation of white-tailed deer in the eastern USA has been linked to the spread of Lyme disease in this region⁷. The patient age groups most commonly affected include children aged 2 through 15 years of age and adults aged 30 to 59 years of age⁸.

Clinical Description

This tickborne, spirochetal, zoonotic disease is characterized by a distinctive skin lesion, systemic symptoms and neurologic, rheumatologic and cardiac involvement that occur in varying combinations over a period of months to years⁸. An initial skin lesion occurs in 60-80% of patients and appears as a red macule or papule that expands slowly in an annular manner, often with central clearing. This distinctive skin lesion is called “erythema migrans” (EM) or may sometimes be referred to as a “bulls eye rash.” EM may be single or multiple. To be considered significant for case surveillance purposes, the EM lesion must be physician diagnosed and measure at least 5 cm in diameter⁹. According to the Infectious Disease Society of America (IDSA), EM is the only objective

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sign of Lyme disease in the United States that is considered to be characteristic enough to allow clinical diagnosis of Lyme disease in the absence of laboratory confirmation⁹.

With or without EM, early systemic manifestations of Lyme disease may include malaise, fatigue, fever, headache, stiff neck, myalgia, migratory, arthralgias and/or lymphadenopathy, all of which may last several weeks or more in untreated patients⁹.

Within weeks to months after onset of the EM lesion, neurologic and nervous system abnormalities such as aseptic meningitis and cranial neuritis—including cranial nerve palsy, radiculopathy, cerebellar ataxia, motor or sensory radiculoneuritis, myelitis and, rarely, encephalitis may develop; symptoms fluctuate, may last for months and may become chronic. In the United States, cranial neuropathy is the most common manifestation of early neurologic Lyme disease⁹. Cardiac abnormalities (including atrio-ventricular block and rarely, acute myopericarditis or cardiomegaly) usually occur around 2 months after onset of EM⁹. Weeks to years after initial disease onset, intermittent episodes of swelling and pain in large joints, especially the knees, may develop and recur for several years; chronic arthritis may occasionally result. Similarly, sometimes following long periods of latent infection, chronic neurologic manifestations may develop and include encephalopathy, polyneuropathy or leukoencephalitis; the CSF often shows lymphocytic pleocytosis and elevated protein levels, while the electromyogram is usually abnormal.

It should be noted that in recent years, the number of cases with documented late manifestations of Lyme disease (including neurologic, rheumatologic and cardiac complications) have appeared to decline compared with earlier reports of the prevalence of these manifestations. IDSA suggests these declines may be due to ascertainment bias in earlier studies, or more successful treatment of early Lyme disease due to better recognition of EM⁹.

Etiologic Agent

The bacterium that causes Lyme disease is *Borrelia burgdorferi*, a spirochete.

Reservoir

Certain ixodid ticks through transstadial transmission⁷. Wild rodents, especially *Peromyscus* spp. in the northeastern and midwestern USA and *Neotoma* spp. in the western USA maintain the enzootic transmission cycle. Deer serve as important maintenance mammalian hosts for vector tick species. Larval and nymphal ticks feed on small mammals, and adult ticks feed primarily on deer. The majority of Lyme disease cases result from bites by infected nymphs.

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Mode of Transmission

The most important and by far the most common mode of transmission is through the bite of an infected tick. In experimental animals, transmission by *I. scapularis* and *I. pacificus* usually does not occur until the tick has been attached for 24 hours or more; this may also be true in humans⁷. Additionally, *B. burgdorferi* can survive in blood products; therefore, patients with suspected Lyme disease should refrain from donating blood until after completing adequate antibiotic therapy^{7,10}. Information on the current criteria for blood donation is available on the Red Cross website <http://www.redcross.org/donate/give/>. Transmission from infected blood products is theoretically possible; however, to date there have been no reports of cases acquiring Lyme disease through blood products¹⁰.

Lyme disease acquired during pregnancy may lead to infection of the placenta and possible stillbirth, however, no negative effects on the fetus have been found when the mother receives appropriate antibiotic treatment¹⁰. There are no reports of Lyme disease transmission from breast milk. Although dogs and cats can get Lyme disease, there is no evidence that they spread the disease directly to their owners. However, pets can bring infected ticks into your home or yard. Consider protecting your pet, and possibly yourself, through the use of tick control products for animals¹⁰.

Incubation Period

For EM, from 3 to 32 days (mean 7 to 10 days) after tick exposure⁷; however, the early stages of the illness may be unapparent, and the patient may present with later manifestations.

Period of Communicability

No evidence of natural transmission from person to person. There are rare case reports of congenital transmission.

Outbreak Recognition

Outbreaks would be recognized as increase in number of cases clustered in place and time.

Case Definition

This surveillance case definition was developed for national reporting of Lyme disease; it is not intended to be used in clinical diagnosis¹¹.

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Clinical presentation

A systemic, tick-borne disease with protean manifestations, including dermatologic, rheumatologic, neurologic, and cardiac abnormalities. The best clinical marker for the disease is erythema migrans (EM), the initial skin lesion that occurs in 60%-80% of patients.

For purposes of surveillance, EM is defined as a skin lesion that typically begins as a red macule or papule and expands over a period of days to weeks to form a large round lesion, often with partial central clearing. A single primary lesion must reach greater than or equal to 5 cm in size across its largest diameter. Secondary lesions also may occur. Annular erythematous lesions occurring within several hours of a tick bite represent hypersensitivity reactions and do not qualify as EM. For most patients, the expanding EM lesion is accompanied by other acute symptoms, particularly fatigue, fever, headache, mildly stiff neck, arthralgia, or myalgia. These symptoms are typically intermittent. The diagnosis of EM must be made by a physician. Laboratory confirmation is recommended for persons with no known exposure.

For purposes of surveillance, late manifestations include any of the following when an alternate explanation is not found:

Musculoskeletal system. Recurrent, brief attacks (weeks or months) of objective joint swelling in one or a few joints, sometimes followed by chronic arthritis in one or a few joints. Manifestations not considered as criteria for diagnosis include chronic progressive arthritis not preceded by brief attacks and chronic symmetrical polyarthritis. Additionally, arthralgia, myalgia, or fibromyalgia syndromes alone are not criteria for musculoskeletal involvement.

Nervous system. Any of the following, alone or in combination: lymphocytic meningitis; cranial neuritis, particularly facial palsy (may be bilateral); radiculoneuropathy; or, rarely, encephalomyelitis. Encephalomyelitis must be confirmed by demonstration of antibody production against *Borrelia burgdorferi* in the cerebrospinal fluid (CSF), evidenced by a higher titer of antibody in CSF than in serum. Headache, fatigue, paresthesia, or mildly stiff neck alone, are not criteria for neurologic involvement.

Cardiovascular system. Acute onset of high-grade (2nd-degree or 3rd-degree) atrioventricular conduction defects that resolve in days to weeks and are sometimes associated with myocarditis. Palpitations, bradycardia, bundle branch block, or myocarditis alone are not criteria for cardiovascular involvement.

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Laboratory evidence

For the purposes of surveillance, the definition of a qualified laboratory assay is

- (1) a positive culture for *B. burgdorferi*, or
- (2) two-tier testing interpreted using established criteria [1], or
- (3) single-tier IgG immunoblot seropositivity interpreted using established criteria [1-4].

Exposure

Exposure is defined as having been (less than or equal to 30 days before onset of EM) in wooded, brushy, or grassy areas (i.e., potential tick habitats) in a county in which Lyme disease is endemic. A history of tick bite is not required.

Disease endemic to county

A county in which Lyme disease is endemic is one in which at least two confirmed cases have been acquired in the county or in which established populations of a known tick vector are infected with *B. burgdorferi*. [to see a map of endemic counties in West Virginia, see [Appendix B](#) in this document).

Case classification

Confirmed: a) a case of EM with a known exposure (as defined above), or b) a case of EM with laboratory evidence of infection (as defined above) and without a known exposure or c) a case with at least one late manifestation that has laboratory evidence of infection.

Probable: any other case of physician-diagnosed Lyme disease that has laboratory evidence of infection (as defined above).

Suspected: a) a case of EM where there is no known exposure (as defined above) and no laboratory evidence of infection (as defined above), or b) a case with laboratory evidence of infection but no clinical information available (e.g. a laboratory report).

Lyme disease reports will not be considered cases if the medical provider specifically states this is not a case of Lyme disease, or the only symptom listed is "tick bite" or "insect bite."

References [for case definition section only]

1. Centers for Disease Control and Prevention. Recommendations for test performance and interpretation from the Second National Conference on Serologic Diagnosis of Lyme Disease. MMWR MMWR Morb Mortal Wkly Rep 1995; 44:590-1.

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3. Engstrom SM, Shoop E, Johnson RC. Immunoblot interpretation criteria for serodiagnosis of early Lyme disease. *J Clin Microbiol* 1995; 33:419–27.
4. Centers for Disease Control and Prevention. Notice to readers: caution regarding testing for Lyme disease. *MMWR Morb Mortal Wkly Rep* 2005; 54:125–6.
5. Centers for Disease Control and Prevention. Lyme Disease — United States, 2003–2005. *MMWR Morb Mortal Wkly Rep* 2007; 56:573–6.

Preventive Interventions

1. Avoid potential tick habitat (such as woody, brushy, or grassy areas) when possible.
2. Minimize exposure by wearing light colored clothing that covers legs and arms so that ticks are more easily seen; tuck pants into socks and apply tick repellent such as 20% DEET to the skin (according to label directions) or permethrin (a repellent and contact acaricide) to pant legs and sleeves (not skin).
3. Many infections from tickborne diseases happen at home—create “tick free zones.” Remove leaf litter and brush around your home and at the edges of lawns. Place wood chips or gravel between lawns and wooded areas. Mow the lawn and clear brush regularly. Keep playground equipment, decks and patios away from yard edges and trees.
4. If working or playing in an infected area, search the total body area daily, do not neglect haired areas, and remove ticks promptly; these ticks may be very small.
5. Remove any attached ticks by using gentle, steady traction with tweezers applied close to the skin to avoid leaving mouth parts in the skin; protect hands with gloves, cloth or tissue when removing ticks from humans or animals. Following removal, cleanse the attachment site with soap and water. For more information on the safe removal of an attached tick, click [here](#).
6. Check pets for ticks regularly; consult with a veterinarian regarding medications effective for controlling ticks.

Treatment

The National Institutes of Health (NIH) has funded several studies on the treatment of Lyme disease. These studies have shown that most patients can be cured with a few weeks of antibiotics taken by mouth. Antibiotics commonly used for oral treatment

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include doxycycline, amoxicillin, or cefuroxime axetil. Patients with certain neurological or cardiac forms of illness may require intravenous treatment with drugs such as ceftriaxone or penicillin¹².

Patients treated with antibiotics in the early stages of the infection usually recover rapidly and completely. A few patients, particularly those diagnosed with later stages of disease, may have persistent or recurrent symptoms. The authors of studies sponsored by the NIH have concluded that these patients may benefit from a second 4-week course of therapy; however, longer courses of antibiotic treatment are not beneficial. Longer courses of antibiotics have been linked to serious complications, including death¹³.

Studies of women infected during pregnancy have found that there are no negative effects on the fetus if the mother receives appropriate antibiotic treatment for her Lyme disease. In general, treatment for pregnant women is similar to that for non-pregnant persons, although certain antibiotics are not used because they may affect the fetus. If in doubt, discuss treatment options with your health care provider.

To view treatment guidelines developed by the Infectious Disease Society of America, click [here](#)⁹.

Surveillance Indicators

1. Proportion of cases with complete demographic information.
2. Proportion of cases with complete clinical information (i.e., presence of physician diagnosed EM or late manifestations).
3. Proportion of cases reported with physician-diagnosed EM that also contains information on county of exposure.
4. Proportion of cases with appropriate laboratory testing (i.e., as defined by the CDC case definition as “Laboratory Evidence”) including copies of lab results submitted to DIDE.

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1. Centers for Disease Control and Prevention (CDC). Surveillance for Lyme disease—United States, 1992 – 2006. *MMWR* 2008;57:1-9.
2. CDC. Notice to Readers Recommendations for Test Performance and Interpretation from the Second National Conference on Serologic Diagnosis of Lyme Disease. *MMWR* 1995;44:590--1.
3. CDC. Notice to Readers: Caution Regarding Testing for Lyme Disease. *MMWR* 2005;54(05):125.
4. CDC. Lyme disease diagnosis. Available at: http://www.cdc.gov/ncidod/dvbid/lyme/ld_humandisease_diagnosis.htm Accessed 14 Sep 2010.
5. PJ Krause, Foley DT, Burke GS, et al. Reinfection and relapse in early Lyme disease. *Am J Trop Med Hyg* 2006;75(6): 1090–1094
6. CDC. Lyme disease statistics. Available at: http://www.cdc.gov/ncidod/dvbid/lyme/ld_statistics.htm Accessed 14 Sep 2010.
7. Heyman, H.L., Ed. (2004). Control of communicable diseases manual, 19th ed.. American Public Health Association, Washington D.C. p. 366.
8. Depeitropaolo DL, JH Powers, and JM Gill. Diagnosis of Lyme disease. *Am Fam Phys* 2005;72(2): 297-304.
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12. CDC. Lyme disease treatment. Available at:
http://www.cdc.gov/ncidod/dvbid/lyme/ld_humandisease_treatment.htm
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13. Holzbauer SM, MM Kemperman and R Lynfield. Death due to community-associated clostridium difficile in a woman receiving prolonged antibiotic therapy for suspected Lyme disease. *CID* 2010;51; 369.

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Lyme Disease Surveillance Protocol

Appendix A: Lyme Disease Case Investigation Toolkit "FORM A" – Tool to assess clinical illness (fax to healthcare provider)

Date:

To:

Dear Healthcare Provider-

The < _____ > County Health Department has been notified of a positive laboratory report of Lyme disease for patient _____ (DOB: ____/____/____)

In order to comply with state and federal infectious disease reporting requirements, we are requesting the following clinical details in relation to this patient's Lyme disease symptoms. Please respond to all of the following questions and return this completed sheet via fax to (304) xxx-xxxx within 72 hours of receipt. Thank you for your cooperation.

A. Date of first symptom onset (month/day/year): ____ / ____ / ____

B. Was an erythema migrans measuring at least 5 cm in diameter documented for this patient?

YES NO

C. Did patient exhibit any of the following symptoms of late-stage Lyme disease?

I. **Rheumatologic/musculoskeletal** (mark all that apply):

Migratory pain in joints, bone, or muscle Brief arthritis attacks
 Prolonged arthritis attacks Chronic arthritis
 No rheumatologic/musculoskeletal symptoms associated with Lyme disease were observed

II. **Neurologic** (mark all that apply):

Meningitis Bell's palsy Cranial neuritis
 Radiculoneuritis Encephalopathy Polyneuropathy
 Leukoencephalitis
 No neurologic symptoms associated with Lyme disease were observed

III. **Cardiac** (mark all that apply):

Myopericarditis Pancarditis Atrioventricular block
 No cardiac symptoms associated with Lyme disease were observed

D. Was this patient diagnosed with Lyme disease?

YES NO

E. Was an antibiotic prescribed for this episode?

YES NO

(for YES, indicate type of antibiotic and # days prescribed: _____)

Comments:

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Appendix A: Lyme Disease Case Investigation Toolkit "FORM B" – tool to assess patient exposure (call patients with EM)

****THIS STEP SHOULD BE LIMITED TO CASES WITH DOCUMENTED EM BY HEALTHCARE PROVIDER****

Optional script

"Hello, this is < >, a (nurse/sanitarian) from the < > County Health Department. I am following up on a recent report our department received about (name)'s Lyme disease illness. In order for us to better understand the risk for Lyme disease in our county, I would like to ask you a few questions about the time leading up to your illness."

A. On what date were symptoms first noticed*? (month/day/year): ____ / ____ / ____

**This question is asked if onset date was not documented in patient's clinical record*

B. Did you travel outside of your home county within 30 days of the start of your symptoms?

YES NO

a. If yes: traveled to

Destination (city, state)	Date left home (month/day/year)	Date returned home (month/day/year)

Note to investigator: if no travel, county of likely exposure is patient's home county)

C. Did you recall finding any ticks on your body during the 30 days prior to the start of your symptoms?

YES NO

a. If yes: tick bite details

Patient's location when tick found (city, state)	Was tick attached? (yes/no/unknown)	Date found (month/day/year)

Thank the patient and end call.

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Appendix A: Lyme Disease Case Investigation Toolkit

PROVIDER QUICKSHEET: LYME DISEASE



IMPORTANT INFORMATION ABOUT SELECTING LABORATORY TESTS

- The West Virginia Office of Laboratory Services provides **FREE** Lyme disease serology testing
 - Method used is enzyme immunoassay (EIA) screen, with reflex to IgM and IgG western blot
 - For more information see:
<http://www.wvdhhr.org/labservices/shared/docs/Serology/Lyme%20instructions.pdf>
 - For specimen submission form:
<http://www.wvdhhr.org/labservices/shared/docs/Micro/Lyme%20Request%20Form.pdf>
 - For questions, call 304-558-3530 ext. 2410
- CDC recommends a two-tier approach for testing serological specimens
 - EIA antibody screen, followed by IgM and IgG western blot if EIA positive
 - Test codes* for Lyme disease EIA with reflex to western blot for the two most frequent reference labs based on reports received in 2009: **Quest** (10672X); **LabCorp** (258004)
- The use of single-tier IgM western blot testing (i.e., without EIA screen) is not recommended
 - False positive results are more likely to occur due to reduced specificity

RESOURCES FOR PATIENTS

- CDC website has several brochures and info sheets for patients:
http://www.cdc.gov/ncidod/dvbid/lyme/ld_resources.htm
- MedLine Plus website contains several categories of information from credible sources:
<http://www.nlm.nih.gov/medlineplus/lymedisease.html>

RESOURCES FOR HEALTHCARE PROVIDERS

- The Infectious Disease Society of America (IDSA) has developed a FREE online CME case study about the diagnosis and management of Lyme disease: available at
<http://lymecourse.idsociety.org/>
- The American Academy of Family Physicians (AAFP) provides a diagnostic guideline to aid healthcare providers in diagnosing Lyme disease: available at
<http://www.aafp.org/afp/2005/0715/p297.pdf>

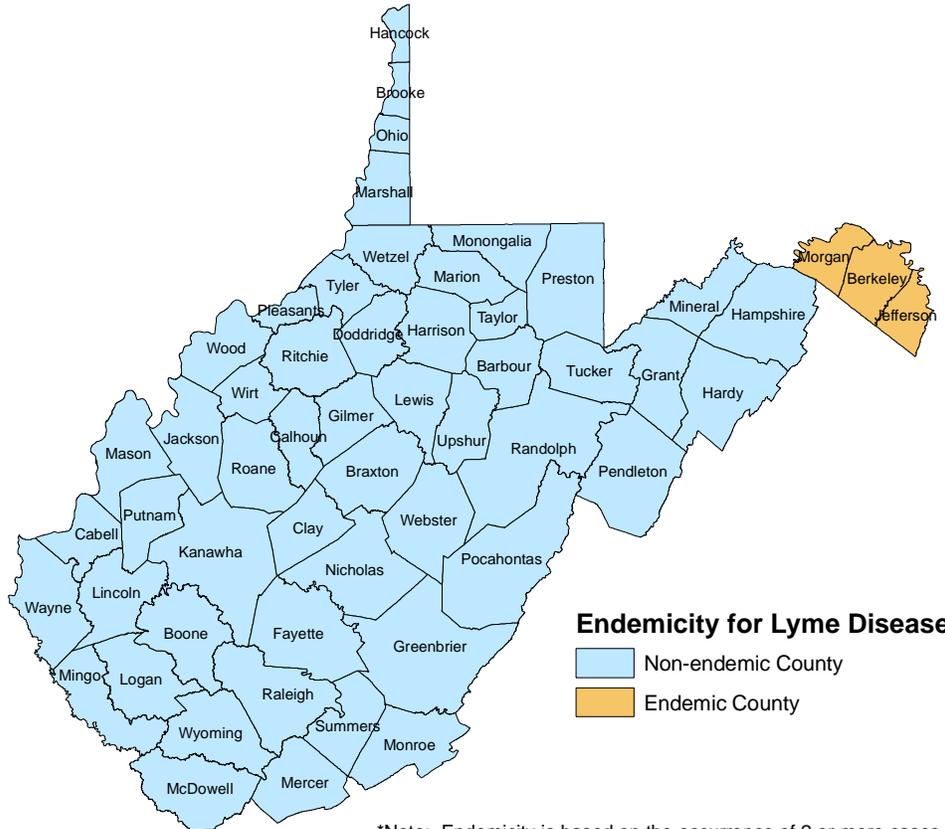
*Test codes subject to change; always check with the laboratory prior to ordering

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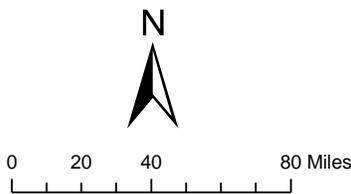
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Appendix B: Counties in West Virginia Considered Endemic for Lyme Disease



*Note: Endemicity is based on the occurrence of 2 or more cases where the county is named as the county of exposure within 30 days of symptom onset.

Endemicity status is considered only on the basis of reported cases where the following criteria are true: 1) case was classified as confirmed; and 2) physician documented erythema migrans (EM) \geq 5cm; and 3) county of exposure was known and was within WV; and 4) case was reported from 2007 through 2009; and 5) Appropriate confirmatory laboratory results per CDC case definition. This restriction criteria resulted in 64 cases, with only 3 counties meeting the definition for endemicity.



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