

*Seventh Edition April 2017*

# **Lyme Disease**

**and associated diseases**

## THE BASICS

**A plain-language introduction to  
tick-borne diseases**

*by*

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*published by*

The Lyme Disease Association of  
Southeastern Pennsylvania, Inc.

**[www.LymePa.org](http://www.LymePa.org)**



# Table of Contents

**Seventh Edition April 2017**

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The information in this publication is true and complete to the best of our knowledge. This booklet is intended only as an introduction to the subject of tick-borne diseases and is not intended to be a substitute for sound medical advice from your physician.

All information presented as fact is based on published medical literature. Some information is speculative and is clearly indicated as such. Because new research is adding to the knowledge-base of tick-borne diseases, no publication can hope to be completely up-to-date. We intend to revise this booklet when necessary, but the reader will benefit from updated information available on the web sites listed in the Resources section.

General Information .....	5
Diagnosis and Testing .....	7
Treatment .....	8
Am I Cured? .....	10
Vaccines .....	10
Prevalence .....	12
Co-Infections .....	12
Anaplasmosis/Ehrlichiosis .....	14
Babesiosis .....	15
Bartonellosis .....	16
Rocky Mountain Spotted Fever .....	17
Other Tick-Borne Diseases .....	17
Lyme Disease in Children .....	18
Lyme Disease in Pregnancy .....	18
Relapse and Cure .....	19
Prevention .....	19
Proper Tick Removal .....	21
Finding a Doctor .....	22
Controversy .....	23
Symptoms List .....	24
References .....	30
About LDASEPA .....	Back Cover

# Lyme Disease

## and associated tick-borne diseases

### THE BASICS

*Answers to the most commonly-asked questions*

#### *General Information*

**Q. What is Lyme disease?**

A. Lyme disease is a bacterial infection, most commonly contracted from a tick bite, that may initially cause a flu-like sickness. Untreated, or inadequately treated, it may cause long-term, persistent illness that can affect many systems of the body. Other tick-borne diseases are often contracted at the same time. Lyme disease is caused by a bacterial spirochete, *Borrelia burgdorferi* (Bb). See a list of symptoms on page 24.

Note that in this booklet, “Lyme disease” will refer to all the common tick-borne diseases present in the U.S.

**Q. How do you get it?**

A. Lyme Disease (LD) is spread primarily through the bite of the deer tick in the eastern and central U.S., and the black-legged tick in the western U.S. The Lone Star tick has also been associated with Lyme disease. Some researchers believe that other ticks and some biting insects such as mosquitoes, fleas, biting flies, and lice may also transmit LD. Babies may be born infected if the mother is infected, or possibly acquire it through breast milk. A blood transfusion with Lyme-infected blood may transmit the disease to the recipient, although this has only been proven for Babesiosis, another common tick-borne disease.

Some medical researchers believe that Lyme, or other tick-borne diseases, can be sexually transmitted, although there has never been any research to prove that. Lyme spirochetes have been found in many bodily fluids.

### **Q. How do I know if I have Lyme disease?**

A. This can be a problem because the symptoms of LD are similar to those of many common infections, and mimic some of the symptoms of other diseases. One sign that is unmistakable is the development of a “bull’s eye” rash around the site of a tick bite. *If you have this rash, you have Lyme disease.*



The Lyme rash varies considerably in different people, but it is typically centered on the tick bite and may range from a fraction of an inch to many inches in diameter. It may be colored anywhere from a mild red to a deep purple. It may appear in a few days or even several weeks after the bite. Two weeks is typical. It may spread to other areas of the body, or there may be additional rashes which may be far from the primary one.

The classic rash has concentric areas of lighter and darker colors and expands with time, but the rash is not always in a bull’s eye form. It is usually painless, but it may be warm to the touch and may itch. Typically it is flat, but some people have raised areas or bumps in the rash. Unfortunately, not everyone develops a rash, and many people fail to notice it if it is in a hard-to-see location, such as the scalp. Fewer than half the people who develop LD recall a rash or a tick bite.

Other symptoms may appear at the same time. These often mimic a cold or flu, with fever, headache, muscle and joint pains, and/or general fatigue, but usually without nasal congestion. Early Lyme can produce a wide range of symptoms, or no symptoms at all, and is different in each person. The varied symptoms may change rapidly, sometimes within hours.

The symptoms may disappear in a few days or weeks (even without treatment), or may be so minor that the infected person barely notices them. Since flu season is during the winter months, and most LD infections occur during the summer, any case of “flu” in summertime should be considered suspect.

### **Q. How long does the disease last?**

Even if these initial symptoms subside, the bacteria can remain in your body and may harm you later. In other cases, symptoms become increasingly severe, requiring prompt medical attention. In persistent Lyme disease, the most frequent symptoms are severe fatigue, pains that seem to

have no obvious cause, and neurological and/or psychiatric problems. The disease may involve multiple body systems and organs. Symptoms may be complicated by other tick-borne co-infections acquired from the same or another tick bite.

Doctors with experience in treating Lyme disease often prescribe no less than six weeks of antibiotic treatment for a tick bite with a bull’s eye rash. If your doctor does not agree with this approach, it may be prudent to search for a doctor who will support extended treatment. Short-term treatment has been associated with a greater likelihood of relapse.

### **Diagnosis**

#### **Q. Is there a test for LD?**

A. According to many experts, there is no reliable test for Lyme disease at this time. Your doctor should base his or her diagnosis on your symptoms, medical history, and your exposure to ticks. Doctors should not rely solely on tests. There are several blood tests available, but all have limitations. The blood test typically used by most family doctors, called an ELISA (or Lyme titer) test, means nothing if it is negative, and it rarely indicates infection if it is performed too early (2 to 6 weeks after the tick bite) because your immune system has not yet made the antibodies the test is looking for.

Patients with persistent LD seldom have a positive ELISA test, possibly because they have ceased to produce the antibodies the test looks for. Many experts believe that the ELISA test is only about 30-50% accurate. While a positive ELISA test is a reasonably reliable indication of infection, a negative test is meaningless.

There are other tests that may be more accurate. The Western blot test for Lyme disease often shows infection when an ELISA test does not. Unfortunately, the U.S. Centers for Disease Control (CDC) have set arbitrary criteria for considering a Western blot test as positive for LD. These criteria were established for statistical analysis of the spread of the disease and were not intended to guide doctors in their diagnosis and treatment. The CDC surveillance criteria are very strict and miss many people with LD. Doctors who use only the CDC surveillance criteria to decide whether or not to treat leave many infected people without proper antibiotic treatment. Even if the test results are not positive by CDC standards, any positive Lyme-specific “bands” are useful indicators of infection.

Another test, PCR analysis, looks for the DNA of the Lyme bacteria in blood, urine, or tissue. Multiple tests are usually required before a sam-

ple is obtained that contains the bacteria. However, in recent years PCR testing has become extremely reliable when positive. Most doctors are unaware of this test.

New tests that culture blood in a growth medium and then use PCR to detect the growing colony of Lyme bacteria show promise, as do tests that employ nanoparticles to bind to Lyme antigens.

Medical experts emphasize that LD requires a *clinical diagnosis*, which means that the doctor should examine the patient for typical LD signs, listen to the patient's history and description of his or her symptoms and use this information to make a determination. Blood tests are usually done at the same time, but should not be relied upon.

According to ILADS (the International Lyme and Associated Diseases Society), if the doctor suspects LD, and sees little reason to believe the patient has some other disease, he or she should begin antibiotic treatment without delay. Of course, doctors should also perform general blood and other tests to rule out other diseases or conditions.

#### **Q. Are all testing labs the same?**

A. No, they are not. Some labs have made special efforts to focus on tick-borne disease testing and they use procedures that make their tests more reliable and sensitive to LD. Use the resources in the back of this booklet to help you identify laboratories that utilize tests that are more sensitive to tick-borne disease organisms, and urge your doctor to send your blood sample to one of the specialist laboratories. Test kit request forms may be available on the laboratory's web site.

### *Treatment*

#### **Q. I had a bull's eye rash and other symptoms, but my doctor said my blood tests showed I didn't have LD, so it must have been something else, right?**

A. *Almost certainly not!* This scenario has caused many people to needlessly suffer for months or years. Left untreated, LD can be a devastating disease. There are few conditions that mimic the LD rash. Lyme-literate doctors suggest starting immediate antibiotic treatment, regardless of the results of any tests.

Often a person suffering from chronic, unsuspected Lyme disease will be diagnosed as having something else, such as chronic fatigue syndrome, fibromyalgia, lupus, multiple sclerosis, Parkinson's disease, Alzheimer's disease, ALS, Crohn's disease, carpal tunnel syndrome,

temporomandibular joint disorder (TMJ), and a wide variety of psychological or psychiatric disorders. Doctors often mistake tick bites for spider bites, but spider bites are actually an uncommon cause of illness. In areas where LD is prevalent, it should be seriously considered before a doctor denies antibiotic treatment.

#### **Q. What happens if LD is not properly treated?**

A. This varies tremendously among individuals. Some people may never have a recurrence of symptoms, while others may become seriously disabled from LD that is untreated or inadequately treated. Serious symptoms can appear immediately or they could take months or years to develop. The most common symptoms are unrelenting fatigue; joint or muscle pain (particularly in the neck, knee, back, or foot); vision or hearing abnormalities; numbness or tingling, particularly at the extremities; facial paralysis; heart damage; psychological disturbances; and stomach problems. (There is an extensive checklist of symptoms in the back of this booklet, and on our web site [LymePa.org](http://LymePa.org). Consider bringing this list to your doctor if you suspect you have LD.)

Untreated LD can result in neurological disorders, crippling arthritis, heart damage, blindness, deafness, psychiatric or psychological disorders, or death.

#### **Q. What is the proper treatment for Lyme disease?**

A. Antibiotic treatment is the simple answer. But the specific answer is still unknown. If they are treated immediately after a tick bite, many patients seem to obtain elimination of symptoms after a course of six weeks of an oral antibiotic like doxycycline. However, it is not known if this treatment permanently cures the disease. If you had a tick bite and a rash, knowledgeable physicians feel that you should be treated with antibiotics as long as symptoms persist. If there is any recurrence of symptoms after treatment, most Lyme-experienced doctors would put you on another course of antibiotics.

A patient who seems to be symptom-free should be vigilant in watching for any recurrence, and so should his or her doctor. Relapses do occur.

At the other end of the spectrum, some patients find no relief at all from a short course of antibiotics, particularly if they have co-infections. Many long-term LD patients given the standard oral antibiotic treatment seem to do fine for years and then suddenly experience the same or new symptoms. Often a stressful life event such as a car accident, head injury, surgery, divorce, or a death in the family can trigger reemergence of symp-

toms mimicking a new infection. Some patients obtain relief with another course of oral antibiotics, while others require long-term treatment with oral, intravenous (IV), or injected antibiotics. Because of the complexity of the Lyme bacteria's life cycle, combinations of antibiotics are often necessary.

In addition to medication, Lyme patients need to develop a good program of exercise and nutrition. Patients on antibiotics need to take probiotics such as acidophilus, which replaces the good bacteria (killed by antibiotics) that are necessary for the body's digestive system to function properly. Many patients also take supplements that help boost the immune system. Consult with your physician on all non-prescription treatments.

**Q. What about “alternative” treatments?**

Many “alternative” treatments for Lyme disease are available. Some, like acupuncture, chiropractic, massage therapy, hyperbaric oxygen treatment, and osteopathy are regulated and considered safe. Many patients benefit from these. Other alternatives are not proven, or could prove to be harmful. These include “Rife Machine” and similar electromagnetic devices, extreme diets, “fever treatment.” etc. Although these fringe treatments could prove to have some validity, further research is needed. You should discuss any of these alternatives with your doctor before starting on one.

**Q. How does my doctor know when I am cured?**

A. Many doctors who treat LD patients avoid using the term “cured” because of the possibility of a relapse in the future. However, most Lyme-literate doctors believe that treatment of persistent infection should continue for at least two months after symptoms have disappeared. Both the patient and the doctor should be prepared to resume treatment if symptoms recur. Patients who do not get well with Lyme treatment may have co-infections (see page 12).

**Q. Isn't there a vaccine for Lyme disease?**

A. There was one, but the manufacturer took it off the market in 2002. Evidence indicated that people with a certain gene might develop an autoimmune arthritic disease from the vaccine. About 30% of the population has this gene, and taking the vaccine could result in severe arthritis. There is no known cure for this condition. The vaccine offered no

protection against other tick-borne disease co-infections that frequently accompany LD.

The vaccine was only about 75% effective and it was not known how long the partial immunity lasted, even with booster shots.

Perhaps a safe and effective vaccine will be developed in the future, but for now, the only way to avoid contracting Lyme disease is to avoid ticks and the other possible sources of infection.

**Q. Once you have had Lyme disease, you're immune, right?**

A. No. You can get Lyme over and over from new tick bites. Each new tick bite can infect you with a new case of Lyme disease or other tick-borne diseases. Some Lyme doctors believe that each subsequent infection makes symptoms more severe and treatment more difficult.

**Q. Why haven't I heard much about Lyme disease until recently?**

A. Lyme disease and its variants have been known throughout the world for at least 120 years (often by different names). There are hundreds of identified strains of the bacteria that cause LD, dozens of them in the U.S. There is proof that prehistoric people were infected with it.

Also, patients with LD may have been undiagnosed or misdiagnosed before doctors became more knowledgeable.

However, it does seem that Lyme disease is much more prevalent now than it was in the past. The main “reservoir” for Lyme disease is the white-footed mouse and other small animals. The Lyme spirochetes live in the blood of the mouse and are passed to a tick when it feeds on an infected animal.

The white-tailed deer is a major host for the ticks that carry LD, and the deer ensure that the ticks have a comfortable place to live and breed. Many areas of the U.S. have had a tremendous increase in the deer population in recent years, so there may be many more ticks in these environments. When the deer population is reduced, the tick population declines in a year or two, and the incidence of LD drops.

The loss of diversity in our wildlife means that ticks are more likely to attach to the mice that harbor the Lyme bacteria. Birds are known to transport ticks to new areas.

### **Q. How many cases of Lyme disease are there really?**

A. No one really knows. Some studies indicate that perhaps only 1 in 75 cases gets into the CDC official statistics. It could be even fewer than that. Many state health departments have decided to only process a portion of the reports, and other states have stopped reporting altogether. We do know that actual number of cases is far, far higher than the 30,000 per year that appear in the CDC statistics.

Research by the CDC in 2014 indicated that the actual number of cases is between 300,000 and 420,000 annually.

### **Q. Why don't doctors know more about Lyme disease?**

A. Some doctors are very up-to-date on the latest research on LD, but many are not. Many doctors are taught that LD is rare and easily-cured and they may not think that it is a serious disease. With thousands of diseases and conditions to learn about, Lyme doesn't seem to rank very high with the majority of doctors, even though it is the most common vector-borne (insect transmitted) infectious disease in the U.S. Nevertheless, it is a major medical problem in the U.S., resulting in billions of dollars in expenses and lost time from work.

### **Q. What can be done to address these issues of poor tests and uninformed doctors?**

A. Organizations such as the International Lyme and Associated Diseases Society (ILADS, an organization of LD health professionals), the Lyme Disease Association, the Lyme Disease Association of Southeastern Pennsylvania, LymeDisease.org, and many others have programs that are aimed at educating the public and doctors on the latest information about the disease. These organizations support state and federal legislation that would fund research into prevention, more accurate tests, and improved treatments for Lyme disease and co-infections.

## *Co-Infections*

### **Q. What are these “co-infections” and “associated diseases?”**

A. The ticks that carry the Lyme bacteria also often carry microorganisms that cause other diseases. The most common “co-infections” are **Anaplasmosis, Ehrlichiosis, Babesiosis, Bartonellosis, and Rocky Mountain spotted fever**. Anaplasmosis, Ehrlichiosis, and Rocky Mountain spotted fever may be cured by the same antibiotics that are

prescribed for Lyme disease. But **Babesiosis** is a different type of disease, caused by a blood parasite and not a bacterium. Antibiotics alone are not effective against Babesiosis. **Bartonellosis** is a bacterial disease, but it requires different antibiotics from those used to treat LD. All are found in ticks, but some, like **Bartonellosis** may be spread more often from flea bites.

### **Q. What about these new tick-borne diseases I have read about?**

A. There are newly-discovered species of tick-borne borrelia that can cause different symptoms. **Borrelia mayonii** causes symptoms similar to Lyme disease but nausea and vomiting are more common with this infection and the rash is different from the bull's eye rash of LD. It has been identified mostly in Wisconsin and Minnesota to date.

**Borrelia miyamotoi** causes recurrent fevers, along with other symptoms common in LD. It has been identified mostly in the Northeastern U.S. The effects of this disease are somewhat different and more intense than in typical Lyme disease. It can be acquired from the bite of a larval deer tick, which are too small for most people to even recognize as a tick. Doxycycline is used to initially treat both of these new LD variants. Little is known about these diseases at this time.

**Powassan Fever** is a serious viral infection that can be fatal. Half of the patients contracting this disease will have permanent neurological damage. This disease causes serious neurological symptoms, including brain and spinal cord inflammation, severe headache, stiff neck, and seizures, as well as many of the other symptoms caused by LD. There is a diagnostic test, but few labs are capable of doing the test. There is no treatment except supportive care. According to CDC records, about 11% of patients die from Powassan Fever. It is still relatively rare, with under 100 cases reported to the CDC since 2004, but there may be many more undiagnosed cases. Powassan Fever can be transmitted in as little as 15 minutes after a tick attaches.

**Heartland** and **Bourbon** viruses are other recently discovered tick-borne diseases, which can be deadly. They have been found mostly in Missouri and Tennessee, spread by infected Lone-Star ticks. There is evidence that other biting insects might also spread these diseases. There is no test and no treatment. They are still rare diseases.

**Morgellons disease** is an emerging disease that causes strange symptoms. It is the least understood and most controversial of the tick-borne diseases. One unique characteristic of Morgellons is the appearance of

fibers growing out of the skin, accompanied by severe itching. Morgellons patients often experience sensations of something crawling under their skin, which leads many doctors to conclude that the patient has a psychiatric problem. However, experiments have shown that dogs can have the same fibers and symptoms.

New organisms such as viruses and microscopic worms are being discovered in ticks. Their role in human illness is not yet known.

**Q. Why do some people develop an allergy to red meat after a tick bite?**

A. This is a new and mysterious condition that seems to be related to the bite of the Lone Star tick. It causes some people to develop a serious, and sometimes life-threatening, reaction to eating beef, pork, and sometimes milk. It is not known yet if this is a permanent condition. Epinephrine may be required in the case of a serious reaction.

Lone Star ticks have spread from the South and Southwest to much of the rest of the U.S. in recent years. They are much more aggressive than deer ticks.

**Q. How does my doctor know if I have these emerging co-infections?**

A. Few doctors are familiar with these other tick-borne diseases. They may fail to recognize the symptoms or test for these diseases, so many people are suffering from untreated infections. The lab tests for these co-infections have many of the same problems as LD tests. Often it is this combination of diseases that makes the patient so mystifyingly ill and unresponsive to treatment. If treatment for LD is unsuccessful, suspect tick-borne co-infections.

**Q. What are the symptoms of Anaplasmosis or Ehrlichiosis?**

A. Like Lyme disease, Anaplasmosis and Ehrlichiosis infections peak during May, June, and July and the symptoms typically appear from a week to a month after infection. The initial symptoms are flu-like and can include high fever, chills, headache, fatigue, and general achiness. Fewer than half of infected people report a rash. The rash is different from a Lyme disease rash; it is usually smaller and may have raised areas. The rash is more common in children than adults. Children may also suffer from swelling of the hands and feet. Other symptoms may develop later, including nausea, diarrhea or constipation, loss of

appetite, cough, stiff neck, confusion, and weight loss. Untreated, the disease can sometimes be fatal in a few weeks, especially in children.

**Q. How are Anaplasmosis and Ehrlichiosis diagnosed?**

A. There are blood tests for Anaplasmosis and Ehrlichiosis, which vary in accuracy and reliability depending on when the test is performed and the lab performing the test. It is difficult to obtain an accurate test result during the first few weeks after infection.

**Q. How are Anaplasmosis and Ehrlichiosis treated?**

A. Anaplasmosis and Ehrlichiosis are usually treated with doxycycline. Most cases respond quickly when diagnosed and treated promptly. However, about 1-2% of these patients will die if treatment is not initiated right away. Like Lyme disease, you can get these diseases over and over again from new tick bites.

**Q. What are the symptoms of Babesiosis?**

A. People with Babesiosis sometimes have no symptoms at all. However, it can be life-threatening for someone with a suppressed immune system. It is also more serious for people over age 50. Symptoms are often the same as for Lyme disease (see list in the back of this booklet), but there may also be a very high fever of up to 104°F, and anemia. Drenching night sweats, chills, severe headaches, fatigue, “air hunger,” and sleep disturbances are common. You can get Babesiosis from a blood transfusion from an infected donor.

**Q. How is Babesiosis diagnosed?**

A. There are blood tests, but the test reliability declines a few weeks after infection. These tests suffer from the same lack of sensitivity that plagues Lyme disease testing. PCR tests for Babesiosis can be useful if positive, but a negative result does not rule out the disease. Examining the red blood cells under a microscope may reveal the parasites, but few diagnostic laboratories are skilled at the tedious job of carefully observing the blood cells.

**Q. What is the treatment for Babesiosis?**

A. It is important to remember that Babesiosis is caused by a protozoan parasite and not by a bacterium, so antibiotics alone will not cure this disease. Many people appear to recover without treatment, but the disease may flare up later. Since Babesiosis is closely related to malaria,



anti-malarial drugs are used to treat it. Usually an atovoquone drug like Mepron or Malarone is used along with an antibiotic such as azithromycin; the combination increases the effectiveness of the treatment. As with most tick-borne diseases, you do not develop any immunity after infection and you can get Babesiosis over and over.

### **Q. What are the symptoms of Bartonellosis?**

A. Early Bartonellosis symptoms are often similar to LD symptoms. There may be a rash, but the rash is different from a Lyme disease bull's eye and may look like long, thin red areas, somewhat like stretch marks. In many people Bartonellosis is a mild disease and the symptoms subside on their own. But in some cases, Bartonellosis may cause on-going fatigue, depression, anxiety, headaches, swollen glands, sore soles of the feet, GI problems, arthritis, generalized aches and pains similar to the other tick-borne diseases, seizures, neurological disorders, and even dementia. Vision loss and eye infections may occur. As with some of the other tick-borne diseases, the symptoms of Bartonellosis tend to come and go.

Some areas have a very high rate of Bartonellosis organisms in ticks, sometimes much higher than the rate for Lyme bacteria. Research has shown that Bartonellosis may be more often transmitted by fleas than by ticks.

### **Q. How is Bartonellosis diagnosed?**

A. There are blood tests, but as with other tick-borne diseases, the tests are often inaccurate. Some doctors report success with a series of PCR tests, but tick-borne Bartonellosis has not been recognized long enough to have a reliable diagnostic testing procedure. Few doctors are familiar with tick-borne Bartonellosis. The cause of tick-borne Bartonellosis is a bacterium similar to one that causes "cat scratch disease," which typically is far less serious and has different symptoms.

### **Q. What is the treatment for Bartonellosis?**

A. Antibiotics are used to treat Bartonellosis, but the antibiotics used to treat Lyme disease are usually not effective for Bartonellosis. As with the other tick-borne diseases, treatment time can be lengthy. Since this disease has been recognized only recently, doctors are still learning which drugs are best. Levaquin, azithromycin, and Rifampin are commonly used to treat Bartonellosis.

### **Q. What are the symptoms of Rocky Mountain spotted fever?**

A. Despite its name, Rocky Mountain spotted fever is far more prevalent in the South and East than it is in the Rocky Mountains. Like Lyme disease, it is caused by a bacterium. Untreated, it can sometimes be a fatal disease. It is spread by dog ticks as well as the deer tick. After two to fourteen days, most infected people suffer from a fever (sometimes 102°F or higher), headache, and achiness. Most people will develop a rash which may begin around the wrists and ankles, but it sometimes starts on the trunk. A classic symptom is a rash on the palms and soles of the feet, but fewer than half of the patients will have that. Untreated, about half of the people infected with Rocky Mountain spotted fever will develop permanent neurological problems.

If you handle a tick while removing it, be sure to wash your hands thoroughly to minimize your risk of infection with RMSF. There are reports of infection simply from contact with an infected tick.

### **Q. How is Rocky Mountain spotted fever diagnosed?**

A. RMSF requires a clinical diagnosis, which means that it is up to your doctor to evaluate your signs and symptoms to determine if you have the disease. Early blood tests are not accurate.

### **Q. How is Rocky Mountain spotted fever treated?**

A. Doxycycline is the recommended antibiotic for RMSF.

### **Q. Are there other co-infections?**

A. New tick-borne diseases are being discovered all the time, and some established diseases are being diagnosed more often. New *Borrelia* species including *Borrelia miyamotoi* and *Borrelia mayonii* are emerging diseases that cause somewhat different symptoms than Lyme disease. Southern Tick-Associated Rash Illness (STARI) seems to share many symptoms with Lyme disease but it may be caused by a different *Borrelia* species.

Colorado Tick Fever, Heartland Virus, and Powassan Virus are caused by viruses and not bacteria. Powassan Virus, which is fatal for a significant number of patients, is carried by deer ticks and can be transmitted after only 15 minutes of tick attachment. There is no treatment, and those who survive usually suffer from long-term, serious neurological damage. Powassan Virus is relatively rare compared to the other tick-borne diseases.

## *Lyme Disease in Children*

### **Q. Can children get Lyme disease and these other tick-borne diseases?**

A. Yes, and because they spend more time outdoors and may not know which areas to avoid, they are at greater risk than adults. Their symptoms may be different from an adult case of LD.

Children infected with LD often initially have a flu-like illness during the summer months and may sleep for a day or more. They often complain that light hurts their eyes. Few children develop the bull's eye rash. Stomach problems are common in children with LD.

With persistent LD, children tire easily and often do not want to participate in physical activity. Most devastating are the cognitive problems LD may bring. Infected children may suddenly develop learning disabilities and/or behavior problems. Researchers have found that LD is the cause of some instances of Attention Deficit Hyperactivity Disorder (ADHD). Some children become physically impaired or even disabled. Teenagers in particular may suddenly exhibit psychological problems, including personality or behavior changes. Adolescents may exhibit self-mutilation ("cutting"). Many children of all ages struggle in school. A sudden change in school performance following an illness is suspect.

### **Q. How are children treated for Lyme disease?**

A. Antibiotics are used to treat LD in children, but the drugs used may be different from those used to treat adolescents or adults. Unfortunately, not many doctors are experienced in diagnosing and treating LD in children.

### **Q. What about pregnant and nursing mothers?**

A. A woman with Lyme or other tick-borne diseases can transmit the infection to her baby during pregnancy. The DNA of Lyme bacteria can be found in breast milk and it may be possible for the baby to be infected from nursing, although this has not been demonstrated in humans. It is suspected that pregnant women infected with tick-borne diseases can suffer miscarriages, or the baby may be born with birth defects.

Unfortunately, many antibiotics are unsafe for pregnant or nursing mothers, so a doctor's choice of treatment is limited. Expectant mothers need to be extremely careful to avoid becoming infected with tick-

borne diseases. Early, aggressive, and continuous antibiotic treatment of the mother during pregnancy appears to be effective in preventing infection of the newborn.

## *Relapse and Cure*

### **Q. Can Lyme disease be cured?**

A. Many patients are cured of Lyme and other tick-borne diseases. However, if they are not treated promptly, it may take months or even years of treatment before the patient feels back to normal and can stop taking antibiotics. Finding the right doctor and following the doctor's instructions are vital for a cure.

### **Q. Can Lyme patients relapse after they are better?**

A. Some patients do have a return of symptoms months or even years after they are successfully treated. This may indicate a new tick bite, or perhaps the infection persisted but was kept under control by the patient's immune system. Often a stressful occasion, such as a death in the family, divorce, or an accident may suppress the immune system, allowing the infection to recur. Patients need to be vigilant and be ready to resume treatment if any symptoms come back.

### **Q. Why does the Lyme infection persist? Don't antibiotics cure it?**

A. Antibiotic treatment started promptly and continued long enough seems to cure 90% of Lyme patients. Sometimes during treatment the Lyme bacteria goes into a "cyst" form where it is not recognized by the immune system and is largely impervious to antibiotics. When the treatment is stopped, or the immune system is suppressed, the bacteria can revert to its normal state and cause symptoms again.

Many bacteria, including the Lyme bacteria, can form "biofilms," which protect them from treatment. Research continues on how to defeat these biofilms and improve treatment effectiveness.

## *Prevention*

### **Q. How do I prevent Lyme disease?**

A. The simple answer is to avoid being bitten by a tick. This isn't a very practical answer for many people who enjoy working and playing out-

doors, and some occupations expose workers to ticks every day. Many Lyme sufferers were bitten in their own yard. But there are some things you can do to reduce your risk.

Ticks are most plentiful in areas where woodlands transition into fields, meadows, or yards. Ticks are often found in tall grass, gardens, or mulch beds. Ticks cannot jump or fly. They are rarely found more than three feet above the ground. Deer paths through the woods are often loaded with ticks. Leaf litter, wood piles, and rock walls are also areas of high tick concentration. Where deer and/or mice are present, ticks are usually abundant.

When you are in such areas, you need to be particularly vigilant to prevent a tick from attaching to your body. There are various insecticides such as permethrin spray for clothing, that may help. Permethrin kills ticks.

You can treat your own clothing with permethrin, which is easy to do and lasts for 6-8 weeks. The clothing can be washed a couple of times before re-treatment is necessary.

Permanently-treated clothing using permethrin is available from several companies and has proven to be very effective. The clothing can be washed at least 70 times and still retain its ability to kill ticks and other insects. It is a very safe compound, originally found in chrysanthemums, that binds with the clothing fabric. It does not work if applied to your skin.

Insect repellents containing DEET are also effective. (On children, for safety, avoid products that contain more than 30% DEET.) Newer products, such as Bio-UD may be safer for children.

Light-colored clothing makes it easier to spot ticks. Wearing long pants, and long-sleeved shirts are helpful. Tuck pant legs into socks to make it more difficult for ticks to crawl up your legs. Walk in the center of trails. After any time spent outdoors, check for ticks while you are out and as soon as you get back. Showering is also helpful. Remember that some of the ticks are extremely small and are almost impossible to see. Putting your clothing in a clothes dryer at high heat will kill ticks in about an hour, but ticks can survive on clothes in a washing machine.

There are products that can be used outdoors to kill ticks. For example, Damminix™ consists of cotton balls soaked in permethrin insecticide inside cardboard tubes that you place around your property where you expect mice may live (wood piles, stone walls, etc.). The cotton will be

used by mice building their nests. The permethrin in the cotton kills the ticks on the mice with minimal danger to people, pets, or wildlife.

Some communities use deer feeders that apply insecticide to the deer as they eat. Tick traps are also commercially available. Some lawn care companies can spray your yard with an EPA-approved acaricide.

Even if you rarely go outside, you can still be infected if your pets bring ticks into the house. Veterinarians recommend a product like Preventic™ collars, Frontline™, Top Spot™ and similar products to minimize the risk. (Use of chemicals is a personal decision and we do not make product recommendations.)

Some researchers think that Lyme can be spread by other biting insects like mosquitoes, horseflies, deerflies, fleas, and lice. Although human infection has not yet been proven, these insects have been shown to carry the Lyme bacteria.

#### **Q. What should I do if I am bitten by a tick?**

A. The tick should be removed promptly by pulling it slowly, straight out with fine-pointed tweezers or a special tick-removal tool inserted as close to the skin as possible. Do not apply heat, alcohol, petroleum jelly, or any other substance. Aggravating the tick in this way may cause it to regurgitate into your blood, increasing your chances for infection. Do not squeeze the tick with your fingers either, as this can force Lyme bacteria into your body. You can use antiseptic on the site of the tick bite after the tick is removed.

Some experts believe that you can be infected almost immediately after the tick attaches to your skin, while others think it takes 24 hours or more to be infected. Research shows that the longer the tick is attached, the greater the likelihood of infection.

#### **Q. What should I do after removing a tick?**

A. Call your doctor. Some doctors will prescribe several weeks of an antibiotic such as doxycycline as a preventive measure.

If you develop symptoms after a tick bite, see your doctor and be sure to get adequately treated for LD and any co-infections you may have contracted. Prompt treatment, for an adequate number of days, is your best defense.

One treatment protocol recommends a single dose of doxycycline to prevent LD. The effectiveness of this treatment has never been duplicated in studies done since the original recommendation in the 1990s.

You can save the tick in a plastic bag or small bottle and show it to your doctor so he can see what bit you. Ticks can be tested for a price, but treatment should not be delayed while waiting for results. A false-negative result could affect your doctor's decision to treat you.

**Q. How do I find a good doctor for Lyme Disease diagnosis and treatment?**

A. Ask at your local Lyme disease support group's meeting, or ask a LD patient who seems to be well-informed. Doctors who treat LD generally prefer to maintain a low profile, since there is controversy surrounding this disease. The Lyme Disease Association maintains a nationwide doctor referral list at [www.lymediseaseassociation.org](http://www.lymediseaseassociation.org). The International Lyme and Associated Diseases Society (ILADS) has a doctor referral service to help patients find ILADS doctors. [LymeDisease.org](http://LymeDisease.org) has set up on-line discussion groups for every state, and these can be helpful in finding a knowledgeable doctor.

LDASEPA will suggest several doctors that you might consider for your treatment. Contact LDASEPA by e-mail ([LymePa@LymePA.org](mailto:LymePa@LymePA.org)) or telephone (610-388-7333).

**Q. I think I have Lyme disease. How can I help my doctor in the diagnosis and treatment?**

A. First, keep careful track of your symptoms. Use the list in this booklet, check them off and take the list to your doctor. It's easy to forget to mention something important during an office visit. Make a copy of your list to leave with your doctor. Even if a symptom seems minor, you need to tell the doctor. He needs all the information to make a diagnosis.

If your doctor seems skeptical of LD, you might want to bring some printed literature that may help him or her. Make sure that what you bring is from a credible source (such as a recognized medical journal), and present it tactfully. The Resource section in the back of this booklet will guide you to appropriate information.

Some doctors respond positively to patient input, but many do not. If you are not satisfied with the way you are being treated by your doctor, it may be time to find one better qualified to help you. Most patients with persistent LD have been to several doctors before getting a proper diagnosis and treatment.

Lyme Disease, perhaps more than most conditions, requires the active participation of the patient if good health is to be regained. Your efforts

to educate yourself about LD will be well worth the time spent, and your doctor may learn as well.

Request and keep copies of all your test results.

Bring notes reminding you of things you need to tell your doctor. Write down your questions ahead of time.

It may be helpful to take someone with you to your doctor appointment, especially if you feel you are mentally impaired by the disease. A friend or family member can help you remember what to tell the doctor, and help keep track of the doctor's instructions.

Tracking your symptoms will be helpful to both you and your doctor. Several different systems for recording your symptoms are available on the LDASEPA web site ([www.LymePa.org](http://www.LymePa.org)).

**Q. Why is there so much controversy regarding Lyme Disease?**

A. That's one question that seems not to have a logical answer. There is a huge difference of opinion between some academic doctors and the doctors who actually treat Lyme patients. Some influential academic doctors have taken a position that LD is hard to catch and easily cured with a few days or weeks of oral antibiotics. They have advocated this position for a long time and they may be ignoring new research. The evidence is overwhelming that LD is a serious and potentially debilitating illness that can become a persistent, long-term disease. The cost of proper early treatment is far less than the expense that chronic LD-sufferers incur in their quest for relief.

Some states have enacted legislation that protects doctors from medical board inquiry when they treat LD patients, as long as they are following a recognized standard of care and no harm comes to the patient. This gives doctors the freedom to treat Lyme patients as they see fit, based on their education and experience rather than "one size fits all" approaches.

The legislation also requires health insurers to pay for the treatment your doctor orders. And most legislation establishes a task force to study and report to the state government on new information about tick-borne diseases.

You can help by letting your state and federal legislators know that you support bills that will help Lyme disease patients and their doctors.

## Symptoms

In addition to Lyme, the co-infections of Babesiosis, Anaplasmosis, Ehrlichiosis, Bartonellosis, and Rocky Mountain spotted fever are prevalent in tick-endemic areas.

Here is a list of symptoms associated with Lyme and tick-borne co-infections. Many of these are symptoms of other diseases as well. An infected person may experience some or many of these symptoms, which is why diagnosis is often difficult. Check the boxes that apply to you. Remember that your doctor is looking for a *pattern* of symptoms.

A tick bite may go unnoticed, especially in the spring and summer, when ticks are tiny. Not all cases of LD are caused by a tick bite. Some may result from placental transmission.

You may have symptoms now, or perhaps you had them in the past. Because LD symptoms often appear suddenly and tend to come and go, each symptom has two check boxes, labeled N and P, for “Now” and “Past.” Take this list with you when you see your doctor.

Even if you have many of these symptoms, it does not necessarily mean you have Lyme disease. Many Lyme symptoms are vague and overlap with many other diseases.

This form is also available on the LDASEPA web site ([www.LymePa.org](http://www.LymePa.org)). You can print it out and bring it to your doctor.

**N P (N = now, P = in the past)**

### Early Symptoms

- Tick bite**
- Rash, often circular, usually spreading.** The “bull’s eye” rash occurs in fewer than 50% of Lyme patients. It may be centered on the tick bite and/or anywhere else on your body.
- Did you experience a flu-like illness, after which you have not felt completely well?
- Extreme or persistent fatigue
- Any type of rash
- Swollen glands
- Unexplained fevers (high or low grade)
- Headache — persistent/severe/intermittent
- Stiff or painful neck

- Bell’s Palsy (facial paralysis, usually one side only)
- Burning or stabbing pains, in odd, shifting places
- Muscle weakness
- “Brain fog” (inability to concentrate; inattention)
- Mood swings, irritability
- Joint pain or swelling
- Joint stiffness, especially back or neck
- Muscle pain or cramps
- Sensitivity to light
- Sore soles (esp. in morning)
- Shortness of breath, “air hunger”
- Night sweats (drenching)
- Unexplained chills
- Heart palpitations or extra beats
- Symptoms change, come and go
- Failure to get a diagnosis for odd symptoms

### Additional Symptoms, often occurring later in the disease

#### Musculoskeletal System

- Arthritis or arthritis-like symptoms
- Creaking, popping, or cracking joints
- Aches or burning in palms and/or soles of feet
- Bone sensitivity, especially the spine
- Shin splints
- Foot pain (ankle, heel, plantar fasciitis)
- Gait disturbance
- Clumsiness
- Pain or swelling moves to different joints
- Backache (unexplained)
- Rib soreness
- Fibromyalgia (generalized muscle pain & tenderness)
- Tendonitis
- In babies, low muscle tone

#### Neurologic System

- Headache — migraine
- Sudden lightning-like jabs

- Tremors or unexplained shaking
- Numbness in parts of the body and/or extremities
- Tingling sensations (like an insect crawling on skin)
- Pinprick sensations
- Weakness or partial paralysis
- Pressure in the head
- Cold or heat intolerance
- Fainting
- Poor balance, dizziness, difficulty walking
- Increased motion sickness
- Warm/cool sensations at various locations
- Twitching of muscles
- Constant low body temperature (below 98.6°F)
- Seizure
- Abnormal blood flow in brain
- Diminished reflexes
- Visual or auditory hallucinations
- Abnormalities of taste or smell
- Odor or taste hallucinations
- Restless legs syndrome (RLS)

### **Mental Capabilities**

- Memory loss, short term
- Memory loss, long term
- Distorted memory
- Confusion
- Declining performance in school or work
- Forgetting how to perform simple tasks
- Speech difficulty (slurred or slow and hesitating)
- Trouble finding the right word
- Drop in measurable IQ
- Dyslexia: letter, number, or word reversals
- Stammering, stuttering speech
- Going to the wrong place, disorientation
- Becoming lost in familiar places
- Dementia (Alzheimer's diagnosis)

### **Psychological well-being**

- Easy frustration
- Unusual depression

- Overly-emotional reactions, crying easily
- Panic, anxiety attacks
- Aggression, rage, road-rage
- Sleeping too much
- Difficulty falling or staying asleep (total insomnia)
- Napping during the day
- Ferocious nightmares
- Obsessive-compulsive behavior
- Suicidal thoughts
- Paranoia
- Disorientation (getting or feeling lost)
- Depersonalization (losing touch with reality, feeling "unreal")
- Bipolar disorder
- Psychosis-like disorders

### **Head, Face, Neck**

- Twitching of facial muscles
- Dental pain (unexplained)
- Painful gums
- Difficulty swallowing
- Hoarseness (unexplained)
- Drippy nose (unexplained)
- Persistent head congestion
- Pressure in head
- Cracks around sides of mouth
- Sore throat
- Scalp rash
- Sinusitis

### **Eyes, Vision**

- "Floaters"
- Double or blurry vision
- Pain in eyes
- Conjunctivitis
- Pressure in eyes
- Flashing lights
- Tearing eyes
- Dry eyes
- Vision loss/Blindness

### **Ears/Hearing**

- Decreased hearing in one or both ears
- Buzzing, clicking, or ringing in ears (tinnitus)
- Pain in ears with no medical cause
- Sensitivity to sound (hyperacusis)

### **Digestive and Excretory System**

- Diarrhea (unexplained)
- Constipation
- Abdominal pain, cramps
- Irritable bladder (trouble starting, stopping)
- Frequent need to urinate
- Upset stomach, nausea, vomiting
- Frequent heartburn
- Bloating
- Gastroesophageal reflux (acid reflux, GERD)
- Anorexia

### **Respiratory/Circulatory System**

- Chest pain (crushing sensation)
- Heart block on EKG
- Mitral valve prolapse
- Heart murmurs
- Elevated blood pressure
- Low blood pressure
- Vasculitis (inflamed blood vessels)
- Cough (non-productive, odd, unexplained)
- Anemia

### **Reproduction**

- Loss of sex drive
- Sexual dysfunction
- Unexplained menstrual pain, irregularity, flooding
- Unexplained breast or nipple pain, discharge
- Testicular or pelvic pain

### **General Well-being**

- Unexplained weight gain or loss
- Malaise
- Unexplained sweating
- Itching

- Continual infections (sinus, kidney, yeast, bladder, etc.)
- Increased sensitivity to allergens
- Exaggerated response to alcohol
- In babies, failure to thrive
- In babies, delayed development

### **Have you been diagnosed with:**

These diseases have symptoms that overlap those of Lyme disease. Patients are sometimes misdiagnosed with these diseases when they may actually be suffering from Lyme disease.

- MS (multiple sclerosis)
- Parkinson's disease
- Fibromyalgia
- Rheumatoid arthritis
- Lupus
- Chronic Fatigue Syndrome
- Crohn's disease
- Carpal Tunnel Syndrome
- Ménière's disease
- Hepatitis
- Epstein-Barr virus infection
- TMJ (jaw pain)
- Gout
- ALS (Lou Gehrig's disease)
- Psychological/psychiatric symptoms
- ADHD (Attention Deficit Hyperactivity Disorder)
- Alzheimer's disease

## References

The following print and on-line references are good sources to begin your quest for more information about Lyme disease. Unfortunately, web addresses often change, or the pages are moved or deleted, so these URLs could be out of date by the time you look for the site. Entering “lyme disease” in any search engine (such as Google, Yahoo, etc.) will provide many sites to investigate. Be aware that there are many sources of poor information on-line (on any topic).

This is a list of sites that seem to be reasonably stable and reliable. All contain many links to additional sites. These sites are a good starting point for your LD education.

[www.LymePa.org](http://www.LymePa.org) (links, general information and news for SE PA area)

[www.ilads.org](http://www.ilads.org) (the largest medical/professional organization devoted to tick-borne diseases; excellent guidelines)

[www.lymedisease.org](http://www.lymedisease.org) (links, general information and news)

[www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org) (general information)

[www.guideline.gov](http://www.guideline.gov) (recognized guidelines for Lyme disease)

## Diagnostic Laboratories

This laboratory specializes in tick-borne diseases. Their web site is also a useful resource for testing information.

IGeneX, Inc. • 800-832-3200 • 797 San Antonio Road • Palo Alto, CA 94303 • [www.igenex.com](http://www.igenex.com)

*For the latest information of diagnostic laboratories, contact LDASEPA.*

## Books and Films about Lyme Disease

**Cure Unknown: Inside the Lyme Epidemic**, Pamela Weintraub, (Book) St. Martin's Press, 2008 (Excellent overview of the history and conflict, plus compelling personal stories.) [www.cureunknown.com](http://www.cureunknown.com)

**Under Our Skin: A Dramatic Tale of Microbes, Medicine & Money**, (DVD) Open Eye Pictures 2008 (Award-winning documentary. DVDs available for purchase.) The follow-up documentary, **Emergence**, revisits some of the patients and doctors from Under Our Skin. [www.underourskin.com](http://www.underourskin.com)

**Bartonellosis: A One-Health Approach to an Emerging Infectious Disease**, Edward B. Breitschwerdt, DVM (DVD) From one of the world's experts on Bartonellosis, this comprehensive talk covers all aspects of this disease. (Available from LDASEPA)

**Compendium of Tick-Borne Disease: A Thousand Pearls**, K. Spreen, D.O. (Book) A comprehensive reference book on Lyme and other tick-borne diseases, written in an engaging style that makes difficult topics easy to understand.

**In the Crucible of Chronic Lyme Disease: Collected Writings & Associated Materials**, Kenneth B. Liegner, MD. (Book) Distilled insights from one of the pioneers of Lyme disease.

**How Can I Get Better?: An Action Plan for Treating Resistant Lyme & Chronic Disease and Why Can't I Get Better? Solving the Mystery of Lyme and Chronic Disease**, Richard Horowitz, MD (books) From an experienced Lyme-treating physician, easy-to-understand information on tick-borne diseases, diagnosis, and treatment.

**Morgellons: The legitimization of a disease: A Factual Guide by the World's Leading Clinical Expert**, Ginger Savely, DNP, MSN, MEd, FNP (Book) Morgellons disease is a mysterious emerging infection of the skin, that seems to be correlated with Lyme disease.

*For the latest information on books and films about Lyme disease, see [www.LymePa.org](http://www.LymePa.org)*

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This booklet is published by

## Lyme Disease Association of Southeastern Pennsylvania, Inc.

**www.LymePa.org**

A not-for-profit 501(c)(3) corporation

An affiliate of the Lyme Disease Association, Inc.



The LDASEPA is an all-volunteer organization founded in 2003, dedicated to improving the lives of people suffering from Lyme and other tick-borne diseases and preventing new cases through education, support, public information, research, and partnership with other organizations with common goals.

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**Publication of this edition was funded by:**

**Generous donations from many of our friends in the Lyme community**