

**This special version of this publication contains end note references for the data.**

**Third Edition September 2003**

# **Lyme Disease**

**and associated diseases**

## **The Basics**

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

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published by

The Lyme Disease Association of Southeastern Pennsylvania, Inc.

[www.lymepa.org](http://www.lymepa.org)

Revised third edition September 2003

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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. A version of this booklet with all references is available from LDASEPA and on-line at [www.lymepa.org](http://www.lymepa.org). 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.

This booklet was written by Douglas W. Fearn with the generous input of Debbie Kliman, Harvey L. Kliman, Larry Linford, Bonnie Sgarro, Christa Vanderbilt, and Jerri-Lyn Wier.

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## Lyme Disease

and associated tick-borne diseases

### The Basics

Answers to the most commonly-asked questions

#### **Q. What is Lyme disease?**

A. Lyme disease is a bacterial infection, most commonly contracted from a tick bite, that often initially causes a flu-like sickness. Untreated, or inadequately treated, it can cause long-term, persistent illness that often affects more than one system of the body.<sup>1</sup> Other tick-borne diseases are often contracted at the same time.<sup>23</sup>

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

A. Lyme Disease (LD) is spread primarily through the bite of a deer tick. Some researchers believe that

other ticks<sup>4</sup> and some biting insects such as mosquitoes, fleas, biting flies, and<sup>5</sup> lice may also transmit LD.<sup>678</sup> Babies may be born infected if the mother is infected,<sup>91011</sup> or possibly acquire it through breast milk. A blood transfusion with Lyme-infected blood may transmit the disease to the recipient.<sup>12</sup> Some Lyme doctors believe that it can be sexually transmitted.<sup>13</sup>

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

A. This can be a problem, because the symptoms of LD are very similar to those of many common infections, and mimic some of the symptoms of other diseases. One sign that is almost 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.*<sup>141516</sup> The bull's eye 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, ugly purple. It may appear in a few days or even several weeks after the bite. It may spread to other areas of the body, or there may be additional rashes far from the primary one. The classic rash has concentric areas of lighter and darker colors, 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.<sup>17</sup> 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 remember a rash or a tick bite.<sup>1819</sup>

Other symptoms usually appear at the same time. These often mimic a cold or flu, with fever, headache, muscle and joint pains, tingling or numbness, and/or general fatigue.<sup>20</sup> Lyme can produce a wide range of symptoms, different in each person. The symptoms may change rapidly, sometimes within hours.

The symptoms may disappear in a few days or a week (even without treatment), or may be so minor that the sufferer barely notices them. Since flu season runs during the winter months, and most LD infections occur during the other seasons, any case of "flu" in warm weather should be considered suspect.

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. Symptoms may be complicated by other tick-borne co-infections acquired from the same tick bite.

You should insist on no less than four weeks of antibiotic treatment if you have a tick bite with a bull's eye rash. If your doctor refuses, see another doctor.

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

A. 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 problems. The blood test typically used by most family doctors, called an ELISA (or Lyme titer) test, will not indicate infection if it is performed too early (2 to 6 weeks after the tick bite).

Patients with long-term LD rarely have a positive ELISA test, possibly because they have ceased to produce the antibodies the test looks for. Most experts believe that the ELISA test is only about 30-60% accurate. However, a positive ELISA test is a reasonably reliable indication of infection.

There are other tests that may be more accurate. The Western blot test for LD often shows infection when an ELISA test does not. Unfortunately, the U.S. Centers for Disease Control (CDC) have set somewhat 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 criteria are very strict and miss many people with LD. Doctors who use the CDC guidelines to decide whether or not to treat leave many people without proper antibiotic treatment.

There are other tests, such as PCR analysis, which looks for the DNA of the Lyme bacteria in blood, urine, or tissue.. Multiple tests are usually required before a sample 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.

Medical textbooks, the FDA, and the CDC emphasize that LD is a *clinical diagnosis*,<sup>21</sup> which means that the doctor should examine the patient for typical LD signs, listen to the patient's 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. 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.

**Q. Are the testing labs standardized?**

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.

**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, and an observation by your doctor of any suspect rash should initiate immediate antibiotic treatment, regardless of the results of any tests.

Often a person suffering from 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 disorders. In areas where LD is common, it should be seriously considered before denying 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 permanently 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.)

[illustration of Bell's palsy]

Untreated LD can result in neurological disorders, crippling arthritis, 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 detailed answer is unknown. If they are treated immediately after a tick bite, many patients seem to obtain elimination of all symptoms after a course of four weeks of an oral antibiotic like doxycycline.<sup>22</sup> If you have a tick bite and a rash, you should have no less than four weeks of antibiotics or longer if symptoms persist. If there is any recurrence of symptoms after treatment, you should insist on another course of antibiotics.

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 treated with the standard oral antibiotic treatment seemed to do fine for years and then suddenly they experience the same or new symptoms. Often a stressful life event such as an accident, surgery, divorce, or a death in the family can trigger reemergence of symptoms mimicking a new infection. Some patients obtain relief with another course of oral antibiotics, while others require long-term treatment with oral, IV, or injected antibiotics.

In addition to medication, Lyme patients need to develop a good program of exercise and nutrition. Patients on antibiotics usually take acidophillus, which replaces the good bacteria (killed by the treatment) necessary for your 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. 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 after all symptoms have disappeared. Both the patient and the doctor should be prepared to resume treatment if symptoms recur.

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

A. There was one, but the manufacturer has taken it off the market. 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.<sup>23</sup> There is no known cure for this condition. Some doctors have seen cases where “cured” or previously undiagnosed LD is reactivated in patients who were vaccinated. There are currently lawsuits against the vaccine manufacturer. The vaccine offered no protection against other tick-borne disease co-infections that frequently accompany LD.

The vaccine was only about 80% effective and it is not known how long the partial immunity lasts.

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. Unfortunately, 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 about Lyme disease until recently?**

A. Lyme disease and its variants have been known throughout the world for at least 100 years (often by a different name). There are in excess of 100 identified strains of the bacteria that causes LD, dozens of them in the U.S.<sup>24</sup> There is even evidence that prehistoric people were infected with it.<sup>25</sup>

However, it does seem that Lyme disease is much more prevalent now than it was in the past. The “reservoir” for Lyme disease is the white-footed mouse—the Lyme spirochetes live in the blood of the mouse and are passed to a tick when it feeds on an infected mouse.<sup>2627</sup> The white-tailed deer is a major host for the ticks that carry LD, and the deer ensure that the ticks and their Lyme spirochetes 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 the environment.<sup>282930</sup> The loss of diversity in our wildlife means that ticks are more likely to attach to the mice that harbor the Lyme bacteria.<sup>31</sup> Birds are known to transport ticks to new areas.<sup>32</sup> Also, patients with LD may have been undiagnosed or misdiagnosed before doctors became more aware of it.

**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 have heard that LD is rare and easily-cured and they may think that it is not 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 insect-borne infectious disease in the US.<sup>33</sup> Nevertheless, it is a major medical problem in the U.S., resulting in billions of dollars in expenses and lost time from work. More than 19,000 new cases are reported to the CDC every year, and it is estimated that at least ten times that many cases are not reported.<sup>34</sup>

**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 national Lyme Disease Association, the Lyme Disease Foundation, Lyme Disease Association of Southeastern Pennsylvania, and many others have programs that are aimed at educating the public and doctors on the latest information about the disease. These organizations are working on federal legislation that would fund research into prevention, more accurate tests, and improved treatments for Lyme disease and co-infections.

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

A. The ticks that carry the Lyme bacteria often also carry microorganisms that cause other diseases.<sup>353637</sup> The most common “co-infections” are Ehrlichiosis, Babesiosis, Bartonella, and Rocky Mountain Spotted Fever. Ehrlichiosis, Bartonella, 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. It’s a sobering fact that new tick-borne diseases are being discovered every year.

Few doctors are familiar with these 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.

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

A. Like Lyme disease, 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 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, loss of appetite, cough, stiff neck, confusion, and weight loss. Untreated, the disease can sometimes be fatal in a few weeks.

**Q. How is Ehrlichiosis diagnosed?**

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

**Q. How is Ehrlichiosis treated?**

A. Ehrlichiosis is usually treated with doxycycline. Most cases respond quickly when diagnosed and treated promptly. Like Lyme disease, you can get Ehrlichiosis over and over again.

**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 depressed 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. Night sweats, chills, severe headaches, fatigue, and sleep disturbances are common.<sup>38</sup> You can get Babesiosis from a blood transfusion from an infected donor.<sup>39,40</sup>

**Q. How is Babesiosis diagnosed?<sup>41,42,43</sup>**

A. There are blood tests, but the test reliability declines after a few weeks of 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.<sup>44</sup>

**Q. What is the treatment for Babesiosis?<sup>45</sup>**

A. It is important to remember that Babesiosis is caused by a protozoan and not by a bacterium, so antibiotics alone will not cure this disease. Many people 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 anti-malarial drug like Malarone or Mepron is used along with an antibiotic such as azithromycin; the combination increases the effectiveness of the treatment. The anti-malarial drugs are very powerful and patients often have a limited tolerance of the side-effects, so treatment may have to be interrupted several times. 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 Bartonella?<sup>46,47</sup>**

A. Bartonella usually starts with a rash and swollen glands. Often it is a mild disease and the symptoms subside on their own. But in some cases, Bartonella may cause on-going fatigue, headaches, swollen glands, 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. Symptoms tend to come and go.

Testing indicates that some areas have a very high rate of Bartonella organisms in ticks, sometimes much higher than the rate of Lyme infection.

**Q. How is Bartonella 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 Bartonella has not been recognized long enough to have a reliable diagnostic testing procedure. Few doctors are familiar with tick-borne Bartonella; the same bacteria causes “cat scratch disease,” which typically is far less serious.

**Q. What is the treatment for Bartonella?<sup>48</sup>**

A. Many of the same antibiotics used to treat Lyme and other bacterial tick-borne diseases are used to treat Bartonella. 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. Some doctors report that antibiotics like Cipro may be effective.<sup>49</sup>

**Q. What are the symptoms of Rocky Mountain Spotted Fever?<sup>5051</sup>**

A. Despite its name, Rocky Mountain Spotted Fever is far more prevalent in the 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 sometimes it 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, 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. Like Lyme disease, RMSF is 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.<sup>52</sup>

**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 what areas to avoid, they are at greater risk than adults. Their symptoms may be very 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.<sup>53</sup> Few children develop the bull's eye rash.<sup>54</sup> Stomach problems are common in children with LD.<sup>5556</sup>

Long-term, they tire easily and often do not want to participate in physical activity. Most devastating for children are the cognitive problems LD may bring. Infected children may suddenly develop learning disabilities and/or behavior problems. Many researchers find 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 exhibit psychological problems.<sup>57</sup> Many children of all ages struggle in school.<sup>58</sup>

**Q. How are children treated for Lyme Disease?<sup>5960</sup>**

A. Antibiotics are used to treat LD in children, but the drugs used may be different from those used to

treat 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 before or after birth.<sup>6162636465</sup> Lyme bacteria can be found in breast milk and it may be possible for the baby to be infected from nursing. Unfortunately, many antibiotics are unsafe for pregnant or nursing mothers, so a doctor's choice of treatment is limited. Expectant mothers need to be extra careful to avoid becoming infected with tick-borne diseases. Fortunately, early and aggressive antibiotic treatment of the mother during pregnancy appears to be effective in preventing infection of the newborn.<sup>6667</sup>

**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 outdoors, 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. Deer paths through the woods are often loaded with ticks. Leaf litter, wood piles, and rock walls are also areas of high tick concentration. When you are in such areas, you need to be particularly vigilant to prevent a tick from attaching to your body. There are various insect repellents such as permethrin spray, that may help. Insect repellents containing DEET are also effective. Light-colored clothing makes it easier to spot ticks. Wearing long pants, long-sleeved shirts, and a hat are helpful. 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.

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 field 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 areas are experimenting with 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 a version of permethrin.

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, and Top Spot to minimize the risk.

Some researchers think that Lyme can be spread by other biting insects like mosquitoes, 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.

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

A. Call your doctor. Some doctors will prescribe three or four weeks of an antibiotic such as doxycycline as a preventive measure.<sup>68</sup> 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.

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. I think I have Lyme Disease. How can I help my doctor in the diagnosis and treatment?<sup>69</sup>**

A. First, keep careful track of your symptoms. Use the list in this booklet to 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.

Charts to track your symptoms over time are available on our web site ([www.lymepa.org](http://www.lymepa.org)).

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.

**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 an 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.

### **Q. Why is there so much controversy regarding Lyme Disease?<sup>70</sup>**

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, life-long disease.<sup>71727374757677787980818283</sup> The cost of proper early treatment is far less than the expense that most LD-sufferers incur in their quest for relief.

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## Symptoms

In addition to Lyme, the co-infections of Babesiosis, Ehrlichiosis, Bartonella, 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 and take the list to your doctor. Remember that your doctor is looking for a pattern of symptoms.

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

You may have symptoms now, or perhaps you had them in the past. Because LD symptoms 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.

Tick bite

Rash basically circular, sometimes spreading. The rash occurs in fewer than 50% of Lyme patients. It may be centered on the tick bite and/or anywhere else on your body.

### Musculoskeletal System

Joint pain or swelling

Joint stiffness, especially back or neck

Muscle pain or cramps

Creaking, cracking joints

Aches in palms and/or soles of feet

Spinal sensitivity

Shin splints

Foot pain (ankle, heel, plantar fasciitis)

Gait disturbance

Clumsiness

Movement of pain or swelling to different joints

Backache

Fibromyalgia (generalized muscle pain)

Herniated disc

Tendonitis

Bone pain

Hand stiffness

Cartilage erosion

In babies, low muscle tone

### Neurologic System

Headache—persistent/severe

Bell’s Palsy (facial paralysis)

Burning or stabbing pains

Tremors or unexplained shaking

Numbness in body and/or extremities

**Neurologic System cont.**

- \_\_\_ Tingling sensations
- \_\_\_ Pinprick sensations
- \_\_\_ Weakness or partial paralysis
- \_\_\_ Pressure in the head
- \_\_\_ Lightheadedness, wooziness
- \_\_\_ Fainting
- \_\_\_ Twitching
- \_\_\_ Poor balance, dizziness, difficulty walking
- \_\_\_ Increased motion sickness
- \_\_\_ Alternating warm/cool sensations at various locations
- \_\_\_ Constant low body temperature
- \_\_\_ Seizures
- \_\_\_ Stroke
- \_\_\_ Abnormal blood flow in brain
- \_\_\_ Brain hemorrhage
- \_\_\_ Abnormal brain waves
- \_\_\_ Diminished reflexes
- \_\_\_ Restless legs

**Mental Capability**

- \_\_\_ Memory loss (short or long term)
- \_\_\_ Confusion, difficulty in thinking
- \_\_\_ “Brain fog”
- \_\_\_ Declining performance in school
- \_\_\_ Forgetting how to perform simple tasks

- \_\_\_ Speech difficulty (slurred or slow)
- \_\_\_ Drop in IQ
- \_\_\_ Dementia
- \_\_\_ Dyslexia, word reversals
- \_\_\_ Stammering, stuttering speech
- \_\_\_ Getting lost going to a familiar place

**Psychological well-being**

- \_\_\_ Mood swings, irritability
- \_\_\_ Unusual depression
- \_\_\_ Panic/anxiety attacks
- \_\_\_ Overemotional reactions, crying easily
- \_\_\_ Aggression, rage
- \_\_\_ Too much sleep
- \_\_\_ Difficulty falling or staying asleep
- \_\_\_ Ferocious nightmares
- \_\_\_ Obsessive-compulsive behavior
- \_\_\_ Suicidal thoughts
- \_\_\_ Paranoia
- \_\_\_ Disorientation (getting or feeling lost)
- \_\_\_ Abnormalities of taste or smell
- \_\_\_ Depersonalization (losing touch with reality)
- \_\_\_ Low self-esteem
- \_\_\_ Bitterness, guilt, alienation
- \_\_\_ Bipolar disorder
- \_\_\_ Schizophrenia-like disorder

**Head, Face, Neck**

- \_\_\_ Stiff or painful neck
- \_\_\_ Twitching of facial or other muscles
- \_\_\_ Painful gums
- \_\_\_ Difficulty swallowing
- \_\_\_ Hoarseness and/or drippy nose
- \_\_\_ Painful teeth
- \_\_\_ Pressure in head
- \_\_\_ Cracks around sides of mouth
- \_\_\_ Sore throat
- \_\_\_ Unexplained hair loss
- \_\_\_ Scalp rash

**Eyes, Vision**

- \_\_\_ Floaters
- \_\_\_ Double or blurry vision
- \_\_\_ Pain in eyes
- \_\_\_ Swelling around eyes
- \_\_\_ Light sensitivity
- \_\_\_ Conjunctivitis
- \_\_\_ Pressure in eyes
- \_\_\_ Flashing lights
- \_\_\_ Tearing and/or dry eyes
- \_\_\_ Vision loss/Blindness

**Ears/Hearing**

- \_\_\_ Decreased hearing in one or both ears
- \_\_\_ Buzzing, clicking, or ringing (tinnitus)

- \_\_\_ Pain in ears
- \_\_\_ Sound sensitivity
- \_\_\_ vertigo, dizziness, difficulty walking
- \_\_\_ Increased motion sickness

**Digestive and Excretory System**

- \_\_\_ Diarrhea
- \_\_\_ Constipation
- \_\_\_ Abdominal pain
- \_\_\_ Irritable bladder (trouble starting/stopping)
- \_\_\_ Frequent urination
- \_\_\_ Upset stomach, vomiting
- \_\_\_ Bloating
- \_\_\_ Hemorrhoids
- \_\_\_ Gastroesophageal reflux (acid reflux)
- \_\_\_ Anorexia

**Respiratory/Circulatory System**

- \_\_\_ Shortness of breath
- \_\_\_ Chest pain or rib soreness
- \_\_\_ Night sweats or unexplained chills
- \_\_\_ Heart palpitations or extra beats
- \_\_\_ Heart block, heart attack
- \_\_\_ Valve prolapse, murmurs
- \_\_\_ Elevated blood pressure
- \_\_\_ Frequent and easy bruising
- \_\_\_ Vasculitis (inflamed blood vessels)
- \_\_\_ Cough (non-productive)

**Reproduction**

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

**General Well-being**

- Extreme fatigue
- Symptoms change, come and go
- Pain moves to different body parts
- Unexplained weight gain or loss
- Malaise
- Chills
- Unexplained sweating
- Any type of rashes on the body and /or scalp
- Swollen glands
- Unexplained fevers (high or low grade)
- Itching
- Continual infections (sinus, kidney, yeast, bladder, etc.)
- Increased sensitivity to allergens
- Exaggerated response to alcohol

- Exaggerated response to sweets
- Nodules under the skin
- In babies, failure to thrive
- In babies, delayed development

Did you experience a flu-like illness, after which you have not felt completely well?

**Have you been diagnosed with:**

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

**Notes for your doctor:** \_\_\_\_\_  
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\_\_\_\_\_

## References

The following print and on-line references are good sources to begin your quest for more information on Lyme disease. Unfortunately, World Wide Web addresses often change, or the pages are moved or deleted, so these URLs could be out of date by the time you go looking for the site. Entering “lyme disease” in any search engine (such as Google, Alta Vista, Yahoo, etc.) will provide many sites to investigate.

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) (medical/professional organization)

[www.lymenet.org](http://www.lymenet.org) (general information, with many links)

[www.lymediseaseassociation.org](http://www.lymediseaseassociation.org) (general information and Lyme-literate doctor referrals)

[www.geocities.com/HotSprings/Oasis/6455](http://www.geocities.com/HotSprings/Oasis/6455) (an important resource with many links)

[www.r09.tdh.state.tx.us/zoonosis/lymepict.html](http://www.r09.tdh.state.tx.us/zoonosis/lymepict.html) (photos of typical Lyme rashes)

[www.medscape.com/medscape/CNO/2000/LymeCS/public/index-Lyme.html](http://www.medscape.com/medscape/CNO/2000/LymeCS/public/index-Lyme.html) (This site requires a simple registration, but it is worth it to obtain excellent medical texts that you can give to your doctor if necessary.)

[www.fairfieldweekly.com/articles/lymedisease.html](http://www.fairfieldweekly.com/articles/lymedisease.html) (Insight into the LD treatment controversy)

[www.columbia-lyme.org](http://www.columbia-lyme.org) (LD research at Columbia University)

Also valuable are Lyme disease organizations like LDASEPA that usually provide free hand-outs at their meetings.

## Diagnostic Laboratories

These laboratories perform tests for tick-borne diseases. Their web sites are also useful resources for testing information.

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

Medical Diagnostic Laboratories • 877-269-0090 • 133 Gaither Drive Suite C • Mt. Laurel, NJ 08054 • [www.mdlab.com](http://www.mdlab.com)

**Books on Lyme Disease and related topics:**

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Everything You Need to Know about Lyme Disease, Karen Vanderhoof-Forschner, John Wiley & Sons, Inc., 1997

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This booklet was written by Douglas W. Fearn and published by  
Lyme Disease Association of Southeastern Pennsylvania, Inc.

[www.lymepa.org](http://www.lymepa.org)

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

An affiliate of the Lyme Disease Association

### **Mission Statement**

The LDASEPA is an all-volunteer organization aimed at 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 organizations with common goals.

### **Public Meetings**

LDASEPA meets on the third Wednesday of each month at the Kennett Friends Meetinghouse, Route 82, 1/2 mile south of Route 1, in Kennett Square, PA. Special presentations are scheduled at other times and places. Visit our web site for information on upcoming events.

Send us your e-mail address to receive meeting notices.

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