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 Unfortunately, World Wide Web addresses often change, or the pages are moved or deleted, so these URLs could be out of date by the time you look for the site. Entering "lyme disease" in any search engine (such as Google, 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 (links, general information and news for SE PA area)

www.LymeDiseaseAssociation.org (general information and Lyme-literate doctor referrals)

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

www.lymedisease.org (links, general information and news for the California area)

www.lymenet.org (general information, with many links, including support group listings)

www.lymeinfo.net (general information)

www.cdc.gov/ncidod/dvbid/lyme/index.htm (the Centers for Disease Control and Prevention)

www.fda.gov (the Food and Drug Administration; search for "Lyme")

www.medscape.com (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. Search for "Lyme")

www.columbia-lyme.org (LD research at Columbia University)

Diagnostic Laboratories

These laboratories specialize in 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

Medical Diagnostic Laboratories • 877-269-0090 • 133 Gaither Drive Suite C • Mt. Laurel, NJ 08054 • www.mdlab.com

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 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.

Q. How do you get it?

A. Lyme Disease (LD) is spread primarily through the bite of the deer tick in the eastern U.S., and the black-legged tick in the western U.S. The Lone Star tick, prevalent in the South and Midwest and spreading elsewhere, 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. Some specialist medical researchers believe that Lyme, or other tick-borne diseases, can be sexually transmitted, although there has never been any research to confirm or deny it. 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 very similar to those of many common infections, and mimic some of the symptoms

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The LDASEPA is an all-volunteer organization 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.

Public Meetings

LDASEPA has regular monthly meetings, and special events featuring the world's top Lyme disease experts. Visit our web site for information on upcoming presentations. SIGN UP ON OUR WEB SITE TO RECEIVE MEETING NOTICES.

Lyme Disease Association of Southeastern Pennsylvania, Inc.
P.O. Box 181
Pocopson, PA 19366
610-388-7333

LDASEPA meets on the third Wednesday of every month at the Kennett Friends Meetinghouse, PA Rt 82 one-half mile south of US Route 1, Kennett Square, PA.

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www.IGeneX.com
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generous donations from many of our friends in the Lyme community

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Lyme Disease

and associated diseases

THE BASICS

A plain-language introduction to tick-borne diseases

by
Douglas W. Fearn

published by
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www.LymePa.org

- ☐ ☐ Malaise
- ☐ ☐ Unexplained sweating
- ☐ ☐ Night sweats (drenching)
- ☐ ☐ Any type of rash
- ☐ ☐ Swollen glands
- ☐ ☐ Unexplained fevers (high or low grade)
- ☐ ☐ 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 disease have symptoms that overlap those of Lyme disease. Patients are sometimes misdiagnosed with these diseases when they may actually be suffering from Lyme.

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

rash. If your doctor does not agree with this approach, it may be prudent to search for a doctor who will support extended treatment.

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 problems. 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).

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 30-60% accurate. The ELISA test is not based on the specific Lyme bacteria strain that is most useful for accurate diagnosis. While a positive ELISA test is a reasonably reliable indication of infection, a negative test is useless.

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 guidelines 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 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.

☐ ☐ Depersonalization (losing touch with reality, feeling "unreal")
☐ ☐ Bipolar disorder
☐ ☐ Other psychosis-like disorder

Head, Face, Neck

☐ ☐ Stiff or painful neck
☐ ☐ Twitching of facial or other muscles
☐ ☐ Dental pain (unexplained)
☐ ☐ Painful teeth
☐ ☐ Painful gums
☐ ☐ Difficulty swallowing
☐ ☐ Hoarseness (unexplained)
☐ ☐ Drippy nose (unexplained)
☐ ☐ Pressure in head
☐ ☐ Cracks around sides of mouth
☐ ☐ Sore throat
☐ ☐ Scalp rash

Eyes, Vision

☐ ☐ "Floaters"
☐ ☐ Double or blurry vision
☐ ☐ Pain in eyes
☐ ☐ Sensitivity to light
☐ ☐ 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

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. Consider bringing this list to your doctor if you suspect you have LD.)

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 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, your doctor should 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 jarring accident, head injury, surgery, divorce, or a death in the family can trigger reemergence of

- ☐ ☐ Shin splints
- ☐ ☐ Foot pain (ankle, heel, plantar fasciitis)
- ☐ ☐ Gait disturbance
- ☐ ☐ Muscle weakness
- ☐ ☐ Sore soles (esp. in morning)
- ☐ ☐ 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 — persistent/severe
- ☐ ☐ Headache — intermittent
- ☐ ☐ Headache — migraine-like
- ☐ ☐ Bell's Palsy (facial paralysis, usually one side only)
- ☐ ☐ Burning or stabbing pains, in odd, shifting places
- ☐ ☐ 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
- ☐ ☐ Lightheadedness, wooziness, vertigo
- ☐ ☐ Fainting
- ☐ ☐ Twitching of muscles
- ☐ ☐ Poor balance, dizziness, difficulty walking, vertigo
- ☐ ☐ Increased motion sickness
- ☐ ☐ Warm/cool sensations at various locations
- ☐ ☐ Abnormalities of taste or smell
- ☐ ☐ Constant low body temperature (below 98.6°F)
- ☐ ☐ Seizure
- ☐ ☐ Abnormal blood flow in brain

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 100 years (often by different names). There are hundreds of identified strains of the bacteria that causes LD, dozens of them in the U.S. There is even evidence 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 sometimes 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 mouse. 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 the environment. 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. 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 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 vector-borne 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. Over 20,000 new cases were reported to the

dence 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.

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. 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. 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. Night sweats, chills, severe headaches, fatigue, and sleep disturbances are common. You can get babesiosis from a blood transfusion from an infected donor.

Preventic™ collars, Frontline™, and Top Spot™ 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.

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.

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?

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

iar with tick-borne bartonella. The cause of tick-borne bartonella is the same bacterium that causes "cat scratch disease," which typically is far less serious and has different symptoms.

Q. What is the treatment for bartonella?

A. Antibiotics 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.

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, 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.