

## I AM PREGNANT AND HAVE LD CAN I INFECT MY BABY?

It is possible for the bacterium to pass from mother to fetus across the placenta, resulting in congenital LD. A link between LD & adverse outcomes in a newly infected untreated pregnant women has been published. Mothers who are treated have perfectly normal babies.

Nursing women with LD often call to ask us whether they should continue nursing. There has been no proved cases of transmission through human milk. There is research that proves that *Bb* can be found in the colostrum of infected cows and mice.

Animals studies have demonstrated that ingestion of *Bb* can result in infection. Some physicians recommend nursing mothers discard breast milk during active infection. Breast feeding can resume after treatment is completed and the woman becomes symptom-free. The decision to do so should be discussed with your physician.

## CAN PEOPLE WITH LD RELAPSE?

Despite treatment, some LD patients experience a relapse of symptoms. Relapses may indicate continued infection. Some people who have a relapse of symptoms may actually be reinfected by another tick-bite or have a co-infection with a different pathogen.

## IS LD SEXUALLY TRANSMITTED?

We receive many inquiries as to whether or not LD can be sexually transmitted. No documented cases of transmission through this route have been found. Conflicting animal research has been published. Co-infection in couples most likely represents co-exposure to the same area.

## WHAT IS THE TREATMENT FOR LD?

The LDF does not advocate any specific treatment regimen. To date, no one protocol for treating LD has been proven to be best. Oral antibiotics are usually an effective treatment for the disease in its early local stage. Disseminated, late, or chronic infection may require higher doses of antibiotics for a longer time. There are different opinions among physicians about which antibiotic should be prescribed, for what duration, and how it should be administered (oral vs. intravenous). Research suggests that chronic LD can be caused by either persistent infection or cured infection that has sparked ongoing autoimmune disease in the patient.

The NIH and CDC acknowledge that there is no treatment protocol for Chronic LD. Your physician or veterinarian may call/write to us and we will place them in contact with other specialists who are knowledgeable about LD.

## EARLY TREATMENT ON TICK-BITE

The LDF Medical Advisory Committee recommends early treatment of a known exposure for a person:

- bitten in an area endemic for LD by an unidentified tick or tick capable of transmitting *Bb*. The *New England Journal of Medicine* published a cost-effective analysis that endorsed treatment of tick-bites in endemic areas,
- bitten by a tick capable of transmitting *Bb*, where the duration of the tick-bite is greater than 4 hours or the tick was improperly removed (e.g. squeezed between the fingers, using petroleum jelly, or mangled),
- at higher health risk (this includes pregnant women, babies, young children, and people with serious health problems).
- who clearly requests early treatment and understands the risks of oral antibiotics. This is a case-by-case decision.

## REASONS FOR EARLY TREATMENT

New scientific evidence, current clinical results, and emerging public health considerations challenge the wisdom of a "wait and see" attitude toward this sometimes difficult to cure disease.

These recommendations are based on the following:

1. No test can prove that the patient has become Lyme bacterium-free, so early treatment is critical.
2. No treatment study has taken into consideration patients with the full spectrum of known disease.
3. Research has shown that the Lyme bacterium can disseminate throughout the body and into the brain in a matter of days. The best time to treat is before this dissemination occurs.
4. Once the bacterium is disseminated, eradication can be difficult and expensive. Some patients become chronically ill. According to one study, 20% of people have brain involvement by the time the rash appears.
5. One published study that recommended not to treat on tick-bite failed to mention that all of the patients removed ticks properly and *before* any potential transmission of infection could occur. It is possible that the patients were not even exposed to infection!
6. An increasing number of people with LD do not return to full function.
7. All of this is preventable by patients conducting frequent tick checks, proper tick removal, and early treatment on tick-bite.
8. The LDF agrees with the CDC and NIH that the final decision for treatment is made jointly between the doctor and patient.

# LDF

## FREQUENTLY ASKED QUESTIONS ABOUT LYME DISEASE



Thank you for contacting the Lyme Disease Foundation (LDF). We receive thousands of letters and calls from the general public, health care professionals, and corporations needing information about Lyme disease (LD). To avoid a delay of several weeks, which occurs when we attempt to respond to detailed inquiries, we have created this pamphlet answering the most frequently asked questions about LD.

# LDF

Lyme Disease Foundation ("LDF")

Suite G 348 Merrow RD, Tolland CT. 06084

1-860-454-8909

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

## ARE THERE TESTS FOR LD? WHAT DO THEY MEAN?

The diagnosis of LD should be a clinical one (based on symptoms) with the test results being another piece of information in a complex picture. There are several laboratory tests used as aids in diagnosing LD. You should be aware that none of these tests are 100% reliable. You should discuss the tests with your physician.

### IMMUNE SYSTEM BASED TESTS

The immune system, in a simplistic form, can be divided into two divisions - the humoral division which produces antibodies and the cell-mediated division which contains T-lymphocyte cells.

Lyme serologic tests (antibody titer) and cell-mediated immunity (T-cell) tests are helpful, but test results are not always conclusive. There is no commonly used test that is 100% reliable in ruling out LD. The Centers for Disease Control, the National Institutes of Health, and the LDF state that LD should be clinically diagnosed and should not be based solely on test results.

The immune system's response cannot kill the bacteria once they have left the bloodstream and entered tissue.

### LYMPHOCYTE STIMULATION ASSAY

This test detects specific immune response cells, T-cells, directed against *Borrelia burgdorferi* (*Bb*) and is considered, by some, to be more specific than an antibody titer. Some researchers consider it to be of no better value than the antibody tests. It is also extremely time consuming and quite expensive.

### ANTIBODY TESTS

#### Titers

ELISA (enzyme-linked immunosorbent assay) & IFA (indirect immunofluorescence assay) are the most commonly used tests. They both measure the level of antibodies in the blood/serum or spinal fluid. These antibodies are produced by your immune system to "fight off" infection. They are created in response to bacteria like *Bb*, the causative agent of LD. There are several methods of detecting antibodies, so different laboratories may yield different results. The cut-off points between negative, borderline, and positive also vary between labs, as do the types of measurements used. Test reagents (substance used to make a chemical reaction) can differ.

### WESTERN BLOTTING

This technique produces a type of graph of the immune system's reactivity to the bacteria. Depending on the type of bands that form on the graph, the lab interprets whether or not your immune system is reacting to the various parts of the Lyme bacterium. Band interpretation is controversial.

### INTERPRETING ANTIBODY TESTS

When considering a negative antibody titer, it is important to understand the concept of a false negative. If you do not have LD, then an antibody test should be negative; since your body will not produce antibodies against *Bb* unless the bacterium is present in your body. This is called a true negative.

A false negative test result occurs when a laboratory test fails to detect any antibodies present in a patient, when in fact the person actually has LD. Because of the current test designs (more specific and less sensitive) false negatives are more common than false positives.

#### Reasons for false negatives include:

- Antibodies against *Bb* are present, but the laboratory is unable to detect them.
- Antibodies against *Bb* may not be present in detectable levels in patients with LD. Reasons are listed below.
  - The patient is currently on, or has recently taken, antibiotics. The antibacterial effect of antibiotics can reduce the body's production of antibodies.
  - The patient is currently on or has previously taken anti-inflammatory steroid drugs (such as those taken to treat rheumatoid arthritis) or certain anticancer drugs. These can suppress a person's immune system, thus reducing or preventing an antibody response.
  - The patient's antibodies may be bound with bacteria, with too few free antibodies available for testing.
  - The patient could be immunosuppressed for a number of other reasons and the immune system is not reacting to the bacterium.
  - The bacterium has changed its makeup (antigenic shift) limiting recognition by the patient's immune system.
  - The patient's immune response has not been stimulated to produce antibodies, i.e. the blood test is taken too soon after the tick-bite (2-6 weeks). Please do not interpret this statement as implying that you should wait for a positive test to begin treatment.
  - The laboratory has raised its cutoff so high that a patient's previously positive test is now borderline or negative.
  - The patient is reacting to the Lyme bacterium, but is not producing the "right" bands to be considered positive.

#### Reasons for False Positive Tests Include:

Cross-reactions do occur with other spirochetal infections (e.g. syphilis, relapsing fever, and dental infections) and some other viral and bacterial infections. False positives appear to be rarer than previously suspected.

### DIRECT DETECTION BASED TESTS

What we need is a direct detection method that detects *Bb* infection. This important advance would allow a definitive diagnosis of the disease, demonstrate the best treatment options (by proving treatment was successful) and improve patient management techniques. It would also differentiate whether ongoing symptoms are due to persistent infection or autoimmunity.

### ANTIGEN CAPTURE ASSAY

This test method is considered investigational. Its aim is to detect a unique protein of the bacterium in the urine of a patient. Antigen detection may be especially useful for detecting LD when a person has been taking antibiotics or when the symptoms are flaring up.

### POLYMERASE CHAIN REACTION

The polymerase chain reaction (PCR) test detects LD bacteria by "multiplying" the number of *Bb* bacterial DNA (genetic material) components to a detectable quantity. The PCR is widely used in many situations and with other bacteria. However, for unclear reasons, some scientists have declared that the use of this test in Lyme is "experimental." PCR research has proven that *Bb* has been in the United States for at least 100 years, based on testing of animal pelts discovered in East Coast museums.

## WHAT DOES THE LD RASH LOOK LIKE?

The characteristic LD rash, erythema migrans (EM), does not appear in all patients. This rash may appear as a "bulls-eye" (having central clearing) or may take numerous other shapes. Between 40% to 60% of light-skinned patients develop the EM rash. This rash may appear as a bruise in people with darker skin. Some people have multiple rashes, which indicates disseminated infection.

## WAYS TO DONATE

Ask your employer to match your donation!

Mail a Check to the LDF.

Workplace - Ask your employer for a Directed Donation card (e.g. United Way or state donation campaigns) and write-in our name and address.

Transfer Stock - Have the stockbroker call us.

Assign Honorariums - Payment issued to the LDF becomes a tax-deductible donation by the payer!

Designate the LDF as your corporate charity

In-Kind - We need equipment, supplies, and services.

In your Will - Have your lawyer call us.