

Interpreting IgeneX Lyme test results.

First of all, the diagnosis of Lyme disease is a *clinical diagnosis*. That means that there is *no one certain diagnostic test* that will give us a “yes/no” answer in every case whether an individual has the disease or not, and that the diagnosis depends not only on the lab, but more importantly, on the clinical history, the environmental likelihood of exposure and the signs and symptoms of disease. The highest certainty is when a person has a known tick bite, develops the characteristic rash which is documented by a photograph or observed by a knowledgeable physician and then goes on to develop the characteristic symptoms. But treatment does not have to wait for the symptoms. Treatment should begin with the observation of the rash, and often is given prophylactically with the onset of tick bite, if the tick bite was received in a Lyme endemic area.

Lyme disease, or *borreliosis*, is caused by a spiral shaped bacteria (spirochete) called *Borrelia Burgdorferi*. There are several other species of *borrelia* (*some say over 100 strains in the USA alone!*) that also cause the same or similar symptoms throughout the world, but in the U.S., this is the most common but by no means the exclusive pathogen causing what is known as “Lyme disease”. This may be why some people have all the symptoms and have “negative” test results. Another reason is because the bacteria can compromise the immune system over time, and effectively hide from the immune system. The longer one has the infection, the more compromised the immune system, and the more likely it is that antibodies will not be strongly reactive to the bacteria.

It is common to do one “screening” test, followed by a more specific “western blot” test. The CDC recommends that if the screening test is negative, the western blot is not necessary. Unfortunately there is not a reliable screening test. A reliable screening test would be positive in all cases of active disease, and even have some false positives, which would be screened out with a second, more specific test. The best screening tests we have seem to be positive only 40% of the time, and sometimes even less than that. There is also tremendous debate among the specialists about what constitutes a “positive” test on the more specific Western Blot test.

The Western Blot test has two parts. The IgM antibody is the first line defense of your immune system to a pathogen and is developed first. There are several IgM “bands” listed, based on the weight, in kilo Daltons (kDa) of the surface protein of the bacteria. There are many surface proteins that the immune system can react to located on parts of the body surface of the spirochete. The double starred ‘bands’ are those that most experts agree do not cross react with other species of bacteria and are considered ‘species specific’ for Lyme disease. There are other ‘bands’ which *other* experts consider species specific that are not double starred, and some of those are highly specific for variants of *borrelia*. Positives in the non-species specific bands can add to the suspicion of Lyme disease, but if only those react, then there is a possibility that you have a different infection. If your test has those bands, I will mention them to you. In most diseases, only in the earliest stages does the IgM test show as positive. In Lyme disease, which has a continuous cyclical course, the IgM bands can be positive throughout the course of the disease, showing a reactivation or an early stage of the disease, become negative and then become positive again later. Many doctors do not know this about Lyme disease, and interpret a negative IgM test as proof that you do not have the illness, even if the IgG is strongly positive.

The IgG antibodies are found in the chronic stage of the illness, and can be found even after you have recovered from the illness. Some clinicians think that if only the IgG is active, a person is “over” the illness and in the recovery phase. This is NOT SO in Lyme disease. It takes 12 weeks for the spirochete to become disseminated throughout the body and the IgG response can be seen as early as six weeks and can persist for years, or become suppressed due to the immunosuppression of the bacteria. Some studies show that up to 50% of people infected with Lyme disease (active in their bodies) will show negative Western Blot test results. This is referred to as “sero-negative” Lyme disease.

The CDC has published Surveillance Criteria, which includes some of the species specific and some of the non-species specific bands in both IgM and IgG, in an effort to track the patterns of outbreak. ***The CDC says on their webpage that they do not intend their surveillance criteria to be used as diagnostic criteria.*** However, many insurance companies, and their “medical experts”, have denied benefits to patients using

the CDC surveillance criteria to “disprove” the diagnosis and deny reimbursement for treatment. This is tragic for the patient as it is very misleading and can deny reimbursement for treatment that can be expensive.

The *borrelia* spirochete not only can compromise the human immune system, but can also effectively hide from it. It is a slow growing organism, and the symptoms are sometimes slow to develop, which is why many people do not know they have the infection for months to years. It can mimic many conditions and affect every organ in the body. When treated with antibiotics, it can change its form to evade death from the antibiotic’s method of killing bacteria. It has the spirochete form which has a cell wall, which many antibiotics are designed to attack, since human cells have a cell membrane. The spirochete can shed its cell wall and exist inside our cells in an “L” form, as just it’s DNA, thus evading the antibiotic. There are antibiotics that can attack it in its “L” form as well, but then it can also “encyst” in a dormant state for months to years, in tissues with low circulation, such as bone and cartilage, waiting for a more favorable environment for growth. Then it can become active again. There are antibiotics and some herbal remedies that can find it in its encysted state. This is why the treatment of Lyme disease is multi-faceted and aggressive. It is also prolonged in cases where the infection has gone on for years undiagnosed and untreated, because the infection is established in many organ systems.

Due to the immunosuppression, the patient often develops opportunistic infections that a healthy immune system would have prevented, such as parasites, Candida, and multiple viruses which complicate the clinical picture. It is also not uncommon to find such patients with thyroid dysfunction, adrenal fatigue and other hormonal problems due to the stress of chronic disease. These require corollary support. They are often nutritionally deficient and often have problems clearing toxins from their system, like mercury, so these should be tested for as well, as they can compromise recovery. In addition, it is not at all uncommon to find that if you are infected with the *borrelia* spirochete, the tick that carried the spirochete, or the sexual partner that transmitted the spirochete to you may also have been infected with any of five or more infectious agents that are commonly found in ticks infected with *borrelia*. Doctors who treat Lyme disease will want to know if you have any of these co-infections before beginning treatment. If you test positive, it would be advisable, while waiting for your appointment with a Lyme specialist to get a Co-infection Panel, as the other infections are often treated first. Co-infections can make the *borrelia* infection worse, and are often easier to eliminate. It will prevent delay in your treatment to have these results in hand when you have your first visit with the specialist, along with one or two other tests that evaluate your immune status, and your ability to clear toxins.

While all of this at first may sound discouraging, to the patient who has gone from specialist to specialist with multi-system complaints and gotten no answers and no help, this may at last, be the answer that makes sense. The road to recovery will not be easy, but there is a road, and there are doctors who are pioneers in these specialties of recovery from chronic multi-system disease. Knowing what you are fighting and having allies is half the battle. I will be happy to provide a supportive role in nutritional support, hormonal support and coordination of specialty consults when needed.

Finally, I would like you to understand that there is a very heated controversy in the United States among physicians about the diagnosis and treatment of Lyme disease in its chronic state. The Infectious Disease Society of America, (IDSA) currently holds the view that Lyme disease is rare and easily treated with a short course of antibiotics, and that long term treatment for chronic Lyme disease is not appropriate. This position has been challenged in court in some states, and they are currently being required to review their treatment guidelines with a new panel of physicians, and to make sure there are no conflicts of interest within the members of the panel. They are also required to include a diverse group of physicians in the panel and to invite public discourse before releasing new guidelines. The International Lyme and Associated Disease Society (ILADS) presents the diagnosis and treatment guidelines which I have outlined in this document. It is your right to know that this controversy exists and what position I endorse in presenting these test results to you.

Sincerely,
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Physician Member, ILADS