

Lyme Disease –The Medical Controversy in Diagnosis and Treatment Lynne Mielke, M.D.

Lyme is caused by a tiny spirochete (corkscrew-shaped) bacteria called *Borrelia Burgdorferi*, or (B.b.), after Dr. Burgdorfer, who first discovered it around 30 years ago. The closest medical model for infection with B.b. is Syphilis – which is also a spirochete. For patients with a new diagnosis of Lyme disease infection with *Borrelia Burgdorferi* or its coinfections *Babesia*, *Ehrlichia*, *Bartonella* and *Mycoplasma*, to name a few, it can be a confusing and overwhelming time. Collectively, these are called TBI – or Tick-Born Illnesses. For the sake of convenience, in the remainder of this document, when I say Lyme, I am referring to any or all of the TBI's. I feel that it is critical for patients and their families to educate themselves on all aspects of this disease, the different options for treatment, and the controversies surrounding this condition. Lyme has been called the Great Imitator, because its symptoms can mimic so many other conditions. Patients are often referred for Psychiatric evaluation because doctors can't figure out what is causing the patient's symptoms. Some patients have no physical symptoms at all and only have cognitive or mental symptoms, including mood swings and anxiety. Others have only mild fatigue. However, in the extreme, Lyme can be completely disabling or even fatal. Unfortunately, most doctors do not have adequate training in Lyme disease, so do not even know how to properly test for it, much less what to do about it if it is found. It is critical to see a "LLD" – "Lyme Literate Doctor" – which in my opinion means a doctor who is a member of ILADS.

There are two main camps in the Lyme disease world – ILADS and IDSA. ILADS stands for the International Lyme and Associated Diseases Society. IDSA stands for the Infectious Disease Society of America. These two medical groups are in active disagreement with each other. I believe that the weight of evidence is on the side of ILADS, and that is the group that I have joined. It is important for patients to realize that this is currently the minority opinion of the mainstream medical community. IDSA is a bigger group, and has the support of the insurance industry, which gives it great power. However, the controlling board of IDSA has been sued for unfairly trying to suppress anyone who disagrees with them, and there has been a lot of political "dirty dealing" going on behind the scenes of IDSA that patients need to be aware of.

IDSA's current position is that Lyme can be treated with 1-2 months of antibiotics alone, and that if a patient's symptoms are not resolved by the end of that time, then they have something else causing their symptoms, like a psychiatric disorder. IDSA refuses to acknowledge that there is chronic Lyme. ILADS doctors know that chronic Lyme is real, and that many patients need antibiotics for months or even years, and sometimes given IV, in order to fully recover. This treatment is of course expensive, so it is understandable that the insurance industry has sided with the one-to-two month only treatment camp. The reality is that if Lyme is caught right after exposure, then 1-2 months of antibiotics is

enough to eradicate it. But if it has already invaded all the tissues in the body and is now a chronic infection, then the short course of treatment is inadequate.

Lyme (infection with *Borrelia*) can infect every tissue in the body, including the muscles, joints, brain, GI tract, eye, heart, etc. By the time of diagnosis, it is usually a chronic infection that causes chronic systemic inflammation and immune suppression. Frequently, patients have been to many doctors without help. Common symptoms include fatigue, aches and pains, headaches, low grade fevers, or sweats. Migrating joint pains and/or cyclic fevers are classic. Only about a third of patients get the classic “bull’s-eye rash” that many doctors ask about. Many patients with Lyme have no memory of a tick bite, because sometimes the ticks are Nymphs, or baby ticks, that are tiny and can bite and then fall off.

New evidence is showing that Lyme can be transmitted by many other means beyond an obvious embedded tick. One important way is in utero, from mother to baby across the placenta. Another is in breast milk, or consuming any raw animal milk. Many feel that it can be sexually transmitted between partners. The TBI organisms have been found in essentially all insects that suck our blood for a living – including fleas, chiggers, sand flies, and mosquitoes. It has not proven if these other insects positively transmit the infection when they bite us (most experts think that this is likely) but they do carry the infections. Anywhere there is wildlife – and this includes mice – there is potential exposure to Lyme. Northern California is loaded with deer, and the deer tick is the best-known carrier of Lyme. People who hike or camp are at risk, but I have seen cases where patients probably got it in their own backyard in the suburbs.

The Lyme organisms don’t stay in the blood stream for long, because the immune system tries to attack them there, so they burrow into the tissues, encapsulate themselves for protection, and hide. Since it is very difficult to detect the Lyme organisms themselves on a blood test, most tests look for our immune reaction to the organism. On the outer surface of *Borrelia Burgdorferi* for example, there are many antigen targets (proteins) that the immune system can make an antibody against. Each one of these antibodies has a different molecular weight, and can be used to detect the presence of the Lyme organism or its cousins (coinfections) on a Western Blot test, that separates out the antibodies into bands based on their molecular weight (measured in kilodaltons, or kda). On the Western blot test, some bands are “double starred”. These are the bands that are the most specific for B.b. The others are less specific for B.b., and can be coinfections, or possibly an immune cross-reaction to some other organism.

The problem in diagnosing Lyme is that the bug itself suppresses our immune response to it, so testing for the immune reaction is an inherent “Catch 22.” However, this is still currently the best method we have to screen for the infection. It is important to know that many patients with documented Lyme can have negative blood tests forever (a false

negative test), so the diagnosis of Lyme is NOT made on the basis of blood tests alone. It is made on the basis of clinical symptoms. Blood tests can be used to confirm the diagnosis, but some definite Lyme patients (proven by tissue biopsy) **never** have a positive blood test.

There are two main criteria used to diagnose Lyme disease via Western Blot. The CDC criteria – which were adopted by the insurance industry and routine laboratories such as Quest and Lapcorp – are very narrow and miss a large percentage of patients with Lyme disease. These criteria were never intended by the CDC to be used for **diagnosis** of Lyme. The CDC developed these criteria for a research study that they were conducting on Lyme disease years ago. Researchers always make the conditions for entry into a research study very narrow and rigid, to keep their study population very homogeneous. But Lyme disease in the real world is anything but homogeneous. Specialty laboratories that test for Lyme (such as Igenex, Clongen, and others) know that there are many important diagnostic bands on the Western Blot (W.B.) test that are not reported - even when they are there - by the routine labs using CDC criteria. This causes many patients with Lyme to be missed when using routine lab tests for diagnosis. Unfortunately, because the insurance industry only covers routine labs using CDC criteria, specialty labs such as Igenex (which are much more accurate) are not covered by insurance.

In addition, since Lyme hides in the tissues and does not stay in the blood stream, over time the immune reaction to Lyme will fade, as the immune system is fooled into thinking that it is gone. Therefore, it is very important to give a patient what I call a “Lyme challenge” for at least one month before testing. The Lyme challenge can be any agent that is known to treat Lyme, given for 2-4 weeks minimum before doing the blood test. These agents essentially kick the bug out of hiding in the tissues and back into the blood stream, as it tries to run away and look for a new place to hide. This allows the immune system in the blood stream to “see” it again, and re-react to it. It takes about 3 weeks to make new IgM antibodies which can show up on the W.B. test. IgG antibodies mean that the infection has been there a long time, and is chronic or possibly in the past. I currently like to use 2-4 weeks of an antibiotic, along with 1-2 Lyme herbs whenever possible for the challenge. This greatly increases the likelihood of the test showing the hidden infection. I tell patients that they can have one of three reactions to the Lyme challenge. They may feel nothing at all (about 40%), feel better (about 40%) or feel worse (about 20%). If they feel worse, the symptoms are often flu-like - with headache, muscle or joint aches and pains, fatigue, fever, etc. These are the symptoms of a Lyme die-off, or Herxheimer reaction (often called herxing) that many patients experience periodically as they undergo Lyme treatment. If the symptoms are unbearable (which is rare) then I lower the dose of the challenge agents, and they are usually able to complete the challenge.

On the Igenex Lyme Western Blot test, patients often get “IND” or indeterminate bands. I tell patients that an IND band on the test is like a weak positive. It isn't fully negative, or

it would have been reported as negative. It means that the immune system was weakly reacting. If the immune system had been a little stronger, or the challenge antibiotics or herbs had been higher dose or given longer, the IND probably would have turned positive. Even one IND double starred band on a negative report can indicate clinical significance, which means possible Lyme. Because Lyme itself weakens the immune response, we sometimes have to “read between the lines” to diagnose it. Often after 3-6 months of antibiotic therapy, a previously negative or indeterminate band on the W.B. test against *Borrelia* or one of the coinfections will turn positive – indicating that the infection was there all along, but the immune system was just previously too weak to attack it. After antibiotic and/or herbal therapy helping the immune system to attack the infections, the immune system has enough reserve to start reacting to the other hidden infections in the body.

Just to complicate matters further, each kind of Lyme coinfection can have multiple different strains, each a little bit genetically different from the other, which means our immune system makes slightly different antibodies to each different strain. It would be prohibitively expensive to test for each one, so we only check for the main type of organism found in each region of the U.S. However, with the frequency that people now move and travel, the infection that a patient has may have come from a different region of the country, which makes proper diagnosis even more difficult.

Many patients who have a weak immune system can be infected with multiple infections at the same time – including Lyme, Lyme coinfections, bad gastrointestinal bacteria, parasites, viruses, and yeast. If a patient has Lyme coinfections, those often need to be treated first or the patient will not adequately respond to the Lyme therapy. The analogy I use is that our immune system is like our armed forces. If our army is trying to fight several wars at the same time, it isn't able to fight any of them effectively. But if we can knock off 1 or 2 of the other infections in the body, then the army will be able to fight the remaining Lyme better.

In order to effectively eradicate this difficult infection, it is critical to have the best treatment from an expert doctor. Lyme doctors frequently treat with two antibiotics at the same time, and often have to rotate them so that the bugs do not become immune to them. Also, many add herbs that possess antimicrobial activity, as well as some homeopathic preparations. It is best to attack this infection from as many different angles as possible at once to increase the chances of success.

For treatment success, you must have the proper antimicrobial agents, but you also must have a healthy body and immune system. This means that diet and nutrition are important. When patients are battling a chronic illness such as Lyme, it is essential that they have optimal nutrition to keep their immune system in peak fighting form. Many patients assume that just because they are eating a relatively balanced diet that they are getting adequate nutrition. Often, this is not the case. The only way to be sure is to do

medical tests of nutrient levels. Vitamins, minerals, amino acids, essential lipids, and even fiber must be present in adequate amounts for patients to function well, and many patients are low in one or more of these essential nutrients without even knowing it. In many cases, IV nutrients, such as IV minerals, vitamins, phosphatidyl choline, and glutathione are necessary and very helpful to Lyme patients. Immune boosting supplements are also very important, such as Epicor, Immpower, Immunomax, Transfer Factors, adequate levels of Vitamin D, etc.

In addition, mostly in adults, normalizing hormone levels is very important. Lyme infection is a chronic stressor to the body. Low thyroid and Cortisol, among other hormones, can contribute to the chronic fatigue that many Lyme patients feel. Optimal hormone levels are also necessary for optimal immune function. Lack of sleep is a big problem in many Lyme patients, preventing patients from healing properly. Adequate Melatonin – an essential sleep hormone that also helps the immune system – is very helpful here as well. Even Estrogen, Progesterone, Testosterone, Growth Hormone, and DHEA have all been shown to be good for the immune system and need to be optimized in patients that show low levels on testing.

In my opinion, detoxification is another essential part of any successful Lyme treatment protocol. Most adults and even children are toxic, and don't know it. Toxins come from many sources, including pollution in our air, food, and water. There are contaminants such as aluminum and mercury in vaccines, mercury in silver amalgam fillings and seafood, lead in toys, paint, and many other products, toxins from plastics in water bottles, pesticides in non-organic food, etc. All toxins are dangerous to our health, many can be carcinogenic in the long run, and **all** of them weaken our immune system. If a Lyme patient is toxic, they will not respond as well as they should to the treatment protocols, and may not recover. Detoxification treatments are specific for the types of toxins that the patient has been exposed to. It is essential to test each patient to find out what kinds of toxins are stored in their body, eliminate any ongoing exposure, and then to design a detox protocol that is specific to their needs. Toxins can be divided into two major categories, heavy metals and chemicals.

1. Heavy Metal Detoxification – Chelation (pronounced key-lay-shun) therapy is the most effective treatment for heavy metal toxicity. There are specific medications that are called chelators. They have a strong binding affinity for metals, and will attach to metals and help the body excrete them through urine and stool. Think of chelators as being like magnets – they are attracted to metals. Chelators can be taken by mouth or as a suppository, but the most effective way is intravenous, or IV. Chelation is very effective at removing the major metal toxins, such as mercury, lead, cadmium, aluminum, antimony, arsenic, and many more. Chelation to remove toxic metals from your body can be a very important step to your overall health and recovery from Lyme.

2. Chemical Detoxification - There are no chelators for chemical toxins, however there are effective ways to aid in excreting them from our bodies. Enhancing the liver's natural detoxification pathways through proper supplements helps. IV glutathione, nutrient and lipid therapy is very helpful. FAR-Infrared Sauna therapy is very important for excreting chemical and metal toxins through sweat. FAR-IR Sauna protocols help in two ways. Chemical and metal detox helps the immune system, and Lyme bugs hate heat. Sauna therapy seems to “kick them out of hiding” so that the immune system and Lyme therapies can kill them more effectively. FAR-IR sauna is more easily tolerated than regular high heat saunas, and is better at stimulating the sweat glands and lymphatic system than regular saunas. FAR-IR sauna protocols are even safe for small children, effective and well-tolerated, and a helpful adjunct to anyone's overall Lyme treatment protocol.

During Lyme therapy, maintaining a healthy GI tract is important. A large percentage of the immune system is housed in the GI tract. Many patients have deficiencies in their gastrointestinal good bacteria, have yeast overgrowth, and even parasitic infections. The long term antibiotic and herbal treatment regimens often required for Lyme can make these problems worse. Lyme patients should have their GI tract closely monitored through proper stool testing every few months for optimal GI health. If the beneficial GI flora are too low, the GI tract cannot function properly, and digestion and absorption of food can become impaired. A leaky gut can ensue, leading to chronic inflammatory IgG food intolerances. This also needs to be monitored through IgG food sensitivity testing approximately every six months while under antibiotic treatment. Probiotic supplementation is essential, but levels of the beneficial bacteria in the stool must be tested. One cannot assume that just because they are taking a probiotic that the levels in the GI tract are adequate. Some patients may even benefit from digestive enzyme supplementation. Maintaining proper gastrointestinal health during Lyme therapy can make a big difference in how a patient feels and functions during their treatment.

Hyperbaric oxygen therapy is another important addition to many Lyme treatment protocols. HBOT allows the patient to breathe higher concentrations of oxygen in a pressurized chamber, which oxygenates tissues at a much higher level that you can achieve even if breathing 100% oxygen at room pressure. HBOT has known anti-inflammatory properties, and any chronic infection – including Lyme – causes tissue inflammation. This inflammation can lead to hypoxia, or low oxygenation of tissues. In the brain, this contributes to many of the cognitive side-effects that Lyme patients experience. HBOT corrects this hypoxia, and can lead to major improvement in the cognitive and physical symptoms seen in Lyme patients. At high pressures, HBOT can even kill Lyme organisms, but many patients do not tolerate the high pressures required to do that. Rented lower pressure chambers that go to 1.3 atmospheres are well tolerated and often potentiate Lyme treatment response. Lyme organisms hate oxygen. When they encapsulate themselves, they are partially protecting themselves from oxygen in the tissues. HBOT has also been shown to enhance immunity. Overall, in my opinion,

HBOT is a helpful addition to Lyme treatment protocols, and can enhance the effectiveness of treatment and decrease the pain and disability that can accompany Lyme.

I recommend that all newly diagnosed patients and their families read many things to educate themselves about what they are up against in this fight. If the patient has Autism, then I recommend reading “The Lyme-Autism Connection.” For a good overview on the herbs used to treat Lyme, “Treating Lyme” by Buhner is good. “New Concepts in Treating Lyme Disease” is good because it has chapters by two of our best local Lyme disease experts that I often refer to. I also recommend that all patients watch the DVD documentary “Under Our Skin” which does a great job of explaining the political and financial conflicts of interest surrounding this condition. Also, the magazine “Lyme Times” is a great overview and resource. The book “Cure Unknown” is a good read. The website www.ILADS.org also has a lot of good information.

I hope that this document has been helpful in introducing new patients to some of the information they need to know about Lyme and its controversies. Every patient has to decide for themselves how they want to proceed in treating this disorder. Education is the best defense.

To your health –

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