

# THE LYME TIMES

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## Conference Consensus



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# 10 Reasons Patients Don't Get Better

Burrascano's former PA shares latest treatment tips

By Jerry Simons, PA-C



In Spring 2009, I wrote my "Top 10 reasons why patients do not get better." I was delighted to see a great response to this innovative approach to helping the sickest patients with Lyme and its associated problems. Persistent Lyme acts much like an auto-immune disease, and this guides much of our current treatment. Based on more than three years of new experience and research, I have updated this famous "Top Ten" list, arranged in order of importance (in my humble opinion).

**1. Bacterial Endosymbionts** have been known to exist for thousands of years. Endosymbiosis happens when a larger cell or bacteria overtakes a smaller one, a "germ within a germ." Insects are famous hosts of endosymbionts. This would help explain why there are many strains of Lyme, and how a co-infection might "pop-up" out of nowhere. The theory of endosymbiosis helps explain the changing picture of Lyme and related co-infections in our most challenging patients. A test for endosymbiosis is under development. Hopefully, when it becomes available, it will revolutionize Lyme therapy.

**2. Immune deficiency.** The entire immune system of a Lyme patient must be fully evaluated. Decreased levels of the natural killer cell CD-57 are not only important in the diagnosis of Lyme, but also play a role in monitoring treatment. Measure levels of immunoglobulins, vitamin C, and complement split products. Immunoglobulin levels should be normal in order for a Western blot test to be properly evaluated; low levels of immunoglobulins almost always lead to a false negative reading on the Western blot. Vitamin C is a vital component to proper immune system health, and should be measured in the blood. Low

levels of vitamin C must be aggressively replaced!

**3. Chronic, drug resistant Babesia and persistent/occult parasitic infection.**

Classic symptoms of *Babesia* include a rapid onset of initial illness, often with sudden onset of high fever, severe headaches, sweats and fatigue; often people remember the moment that they got sick. Obvious sweats, usually at night. Air hunger, the need to sigh and take a deep breath; dry cough without apparent reason. Headaches can be severe – dull, global (involves the whole head, described like the head is in a vise). Fatigue is prominent, does not clear with rest, and is made worse with exercise. Mental dullness and slowing of reactions and responses.

Dizziness is more like a tippy feeling rather than vertigo or orthostasis. Symptoms cycle rapidly, with flares every four to six days. Ear complaints: fullness, ringing (do not confuse with side effects from azithromycin). Hypercoagulable states are often associated with *Babesia* infections – blood thinners are often beneficial.

Many are resistant to MEPRON or MALARONE, and report having taken multiple courses of these medications. Artemesia (including the prescription version COARTUM) may be useful, but Artemisinin is effective!

Chronic parasites are not always just intestinal (think of FL 1953). With this in mind, testing for parasites in the stool is difficult. Often a trial of VERMOX or ALBENZA is given to gauge its effect. This may be combined with the parasite detox product PARAGONE. Parasite therapy is often followed up with charcoal capsules.

**4. Other co-infections.** A majority of chronic patients are found to have occult and persistent co-infections, especially *Bartonella* and *Mycoplasma*. Often a therapy approach must be driven by symptoms rather than lab work. The northeast has been experiencing a resurgence of Rickettsial infections as well (the family of Rocky Mountain Spotted Fever infections). Do not forget to investigate chronic viruses and

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chlamydia.

Lastly, it is vital that the body not see the same antibiotic treatment for too long, as resistance, cysts, and side effects develop. Consider changing the drug, the dose, and the timing regularly to keep the germs responsive to therapy. During co-infection therapy, Bicillin is an excellent and effective therapy, one to three injections a week, and 4-5 injections during a Herxheimer week.

**5. Candida.** Chronic systemic candida infection is being recognized as a more important issue in the management of Lyme than previously assessed. It has been studied by the Jeffrey Modell Foundation with respect to immune deficiency. Candida can be assessed by symptoms (vaginal yeast, bloating, loose stools, coated tongue); chronic candida can trigger persistent flu-like symptoms, increasing fatigue, and failure of standard Lyme therapy. I have seen a high rate of resistance to the commonly used yeast medications including Nystatin and Diflucan.

In any patient who has been on antibiotics for more than a year, I require a complete skin test (a candida provocation neutralization test) to assess the sensitivity to candida. High levels of candida lead to antibiotic resistant, cyst forms, failure of antibiotic therapy, and significant fatigue and flu symptoms. The proper diet, a variety of probiotics, and pulsing anti-candida drugs (Sporanox, VFEND, Diflucan, Nizoral) has been found effective. To my delight, many patients have successfully completed this aggressive therapy and have remained significantly improved, often using antibiotics as a once a month pulse dose to cover any flare ups.

**6. Cysts and biofilms.** Especially in patients who have had previous inadequate doses or inadequate length of treatment, Lyme can form an "L-form" or a cyst. At this point, the infection becomes resistant to antibiotic therapy. Flagyl is often required. If Flagyl or Tindamax is given (without triggering a "J. Herx" reaction, consider co-infections. A classic sign of a cyst form is when there is a plateau in Lyme therapy and no signs of co-infection. Biofilm therapy should be taken long-term.

**7. Vasculitis and hypoxia.** Greater than a decade of brain SPECT scanning

has confirmed vasculitis in chronic, neurologic Lyme. If you have persistent "brain fog," headaches, or similar central nervous system complaints, consider having a brain SPECT scan. Be sure the institution has a modern "three headed scanner" as well as a radiologist who is familiar with the unique patterns of Lyme. If the SPECT scan is abnormal, it may be appropriate to consider another brain scan after the IV administration of diamox, an osmotic diuretic and vasodilator. Diamox has been shown to help reduce or reverse vasculitis. Reversing the vasculitis will allow therapy to adequately circulate throughout the body.

A simple oxygen concentrator may help patients sleep. It is well documented that Lyme cannot survive in an oxygen-rich environment (thus the reported success of hy-

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perbaric therapy for Lyme). The use of 2-4 liters per minute of oxygen has caused significant Herxheimer reaction in patients, even those not on antibiotics.

The use of daily oxygen supplementation has helped with the management of headache and fatigue. It is accessible, easy to use on a daily basis, and often covered by insurance. In more severe cases, hyperbaric oxygen is still indicated. Exercising while using nasal cannula oxygen is greatly effective. If active *Babesia* is suspected, consider delaying oxygen use, since patients with *Babesia* who use hyperbaric oxygen have been known to get worse!

**8. Endocrine dysfunction.** Chronic illness can cause stress on the endocrine system, especially the adrenal gland. Early disease causes an overactive adrenal gland, with many symptoms of excessive

adrenaline. Over time, chronic illness weakens the adrenal and often triggers adrenal insufficiency.

High levels of cortisol (a natural steroid) are very detrimental to Lyme therapy and must be addressed. Cortisol may be measured by serum levels as well as saliva and urine. For adrenal insufficiency, saliva testing is used. If abnormal, it is often followed with a "cortrosyn stimulation test" to assess the overall health of the adrenal gland.

Poor thyroid function is also a vital issue. Many Lyme patients present with symptoms of low thyroid function. In the past, a common approach was to replace the T3 with cytomel or compounded T3. Since a majority of Lyme patients with thyroid symptoms have low levels of iodine, I test for that with a skin or urine test. Patients often respond well to doses of daily iodine or additionally low dose T3.

**9. Vitamin deficiency.** Chronic illness is famous for depleting vitamin stores. The most famous include magnesium and the family of B vitamins (1,6,12 especially). In addition, I have been checking patients for serum levels of Coq10 (should be at least 2.5) and vitamin D (should be a minimum of 32, ideal for infection is 50-80). In patients with visual symptoms, checking a blood level of vitamin A is very helpful, as too little or too much many contribute to ocular problems. Be sure your iron (ferritin) scores at least 50. Since low vitamin levels often hint at leaky gut/dysbiosis, consider a stool test.

**10. Neurotoxins and mold illness.** Chronic Lyme can leave behind neurotoxic effects that can complicate therapy or hinder recovery. Most patients will require therapy for neurotoxins at some point in their care. Neurotoxin therapy, such as questran, is incredibly effective when combined with Teasel Root (potent herb against Lyme--common brand SpiroNil), candida therapy, and home oxygen.

It is *vital* to develop a combined approach to Lyme therapy. All of the above need to be addressed together. The patient also benefits from an alkaline, low carb diet and appropriate exercise program.

*This check list is based on Simon's years of patient observations and study. Discuss your personal "Top 10" with your provider.*