



LYME TIMES

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Ask The Expert

By Jerry Simon, PA

Dear Jerry,

Question:

Why Don't Some Lyme Patients Respond to Therapy?

Answer:

"Top 10" Reasons Patients Don't Respond to Therapy

Over the last year, I have developed a "Top-10" checklist of potential problems that I try to identify when a Lyme patient does not respond to therapy as expected. Listed here are the ten issues that I consider in my examination in order of importance...in my own humble opinion!

1. Co-infections. A majority of chronic patients are found to have occult and persistent co-infections, especially *Bartonella*, *Mycoplasma*, and *Babesia*. Often therapeutic decisions need to be driven by symptoms rather than lab work. As discussed at the fall 2008 ILADS meeting, *Bartonella* and *Mycoplasma* play the most significant role in patients who are severely ill. So for patients with chronic tick borne diseases (TBD's), I first focus on *Bartonella* and *Mycoplasma*, then *Babesia* and *Ehrlichias*. In the northeast, we have been experiencing a resurgence of rickettsial infections (the family of Rocky Mountain Spotted Fever). Remember to investigate both chronic viruses and Chlamydia. Lastly, it is vital that the body not experience the same antibiotic treatment for too long as resistance, cysts, and side effects may develop. Consider changing dose, timing, and drug regularly to keep the germs responsive to therapy. During co-infection therapy, an excellent and effective therapy for Lyme coverage is injectable bicillin, 1-3 injections a week, and 4-5 injections during a Herxheimer week.

2. Cysts. Especially in patients who have had previous or inadequate treatment (inadequate doses or inadequate length of treatment), Lyme can form an "L-form" or a cyst. The infection can then become resistant to antibiotic therapy. Flagyl is often required. If there is no Herxheimer reaction, consider the possibility of a co-infection. A classic sign of a cyst form is a plateau in Lyme therapy and no signs of co-infection.

3. Vasculitis and Hypoxia. A decade of Brain SPECT scanning in chronic neurologic Lyme has shown 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 familiar with the unique pattern of Lyme. If the SPECT scan is abnormal, an appropriate next step may be another brain SPECT scan following 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.

In a very exciting development, I have been prescribing a simple oxygen concentrator for many patients to sleep with at night and during the day. It has been well documented that Lyme bacteria cannot survive in an oxygen rich environment (thus the success of hyperbaric therapy for Lyme). The use of 2-4 liters per minute of oxygen has caused significant Herxheimer type reaction in patients, even those not on antibiotics. The use of daily oxygen supplementation has also helped with the management of headache and fatigue symptoms. It is accessible, easy to use, can be used on a daily basis, and is often covered by insurance. In more severe cases, hyperbaric oxygen is still indicated. Expect significant Herxheimer reactions on oxygen!

4. Adrenal dysfunction. Chronic illness from these infections can cause great stress on 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) is very detrimental to Lyme therapy and must be quickly addressed. Cortisol is measured by 9 am and 4 pm serum levels, and can be measured in saliva and urine as well. For adrenal insufficiency, saliva testing is used. If abnormal, a "Cortrosyn Stimulation test" may be administered to assess the overall health of the adrenal gland.

5. Immune deficiency. Decreased levels of the natural killer cell CD-57 is not only important in the diagnosis of Lyme, but also plays a role in monitoring treatment. Equally important is to measure levels of immunoglobulins. Remember that immunoglobulin levels should be normal in order for a Western Blot test to be properly evaluated.



Low levels of immunoglobulins almost always leads to a false negative reading on Western blot. There are many other immune tests to consider, but NK cells and immunoglobulins are an appropriate first start. 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.

6. **Candida.** Chronic Candida infection is becoming recognized as a more important issue in the management of Lyme disease than previously assessed. Candida can be assessed by symptoms (vaginal yeast, bloating, loose stools, coated tongue). But chronic Candida can trigger persistent flu-like symptoms as well, 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. For any patient who has been on antibiotics for more than a year, I require a Candida provocation neutralization test, a skin test to assess the "tissue load" of Candida in the system. 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 Sporanox and Nizoral has been found to be very 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.

7. **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 at least 32). In patients with visual symptoms, checking a blood level of vitamin A is helpful, as too little or an excessive amounts many contribute to ocular problems. Be sure your iron stores (ferritin) are at least a score of 50.

8. **Deconditioning.** This is a nice way of saying Lyme patients who are out of shape have a difficult time getting better. Patients require regular non-aerobic exercise, preferably under the guidance of a professional familiar with their condition. Patients who do not stay active do not get better. Even doing gentle range of motion with cans of soup in your hands is a good start. A diet rich in steamed veggies and lean protein, coupled with elimination of nightshade foods and high glycemic index carbohydrates are vital to improving overall health, minimizing weight gain, and enhancing medication effectiveness. More on this in a future article.

9. **Neurotoxins.** It is well documented that chronic Lyme can leave behind neurotoxic effects which can complicate therapy or hinder a full 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 the use of the herb Teasel Root (a potent herb against Lyme - common brand SpiroNil), candida therapy, and home oxygen.

10. **Thyroid function.** 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. I have recently begun testing patients for low levels of iodine (skin test or urine test). To my surprise, I have seen that a majority of Lyme patients with low thyroid symptoms have low levels of iodine. These patients often respond well

to 25mg of iodine daily; if no response is noted, the addition of a low dose T3 in the morning and as needed in the afternoon, has yielded great success.

A combined approach to treating Lyme disease is key to success. The areas of concern expressed in my checklist should be addressed altogether. Remember, this approach reflects my observations over nearly 13 years of studying, observing and treating patients with chronic Lyme. Always ask your provider what they feel is your own personal "Top 10" problem areas. Discuss with your health provider any treatment suggestions you might want to adopt.

Jerry Simons is a physician assistant currently practicing in New York. He worked with Dr. Joseph Burrascano from 1995 until 2006.

**Wonderful!
Awesome!
Incredible!
Amazing!**

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- **Resources** – Doctor Referrals, Children, Insurance Disputes, Professional Education Grants
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