Frequently Asked Questions

The following is my opinion based on both my personal clinical experience and my interpretation of published medical literature

1. **What is Lyme disease?** Lyme is an illness caused by Borrelia burgdorferi, a bacteria which is classified as a spirochete. It can cause anything from long-term infection without symptoms to chronic illness ranging from mild to severe. As ticks can transmit many pathogens at the same time, Lyme is increasingly thought of collectively, as other infections which are termed 'co-infections' are often present in the same patient. Some common co-infections include bartonella, babesia, anaplasma, and ehrlichia. In addition to co-infections, borrelial infections can occur with bacteria that are cousins to Lyme but are technically not Borrelia burgdorferi. These are non-Lyme borrelial infections which can produce the same range of symptoms as Lyme disease and for which testing is not routinely available.
2. **Which are the most common vector-borne infections that become chronic?** Lyme and bartonella. There is some evidence for persistent babesiosis despite treatment, but less so than for both Lyme and bartonellosis. It is my opinion that non-Lyme borrelial infections will have similar potential for chronicity, as some documentation for this has already been published, but the literature on the topic is new and so not nearly as robust as that for B. burgdorferi.
3. **What is bartonella and how do I differentiate it from Lyme?** Bartonella is a different class of bacteria than Lyme, but causes many of the same symptoms. It's spread by the same tick, but other bugs can spread it as well, such as fleas and lice. It's even been published to have been spread by ant and spider bites. It is a very close cousin to the generally more serious brucella, which causes brucellosis. Brucellosis is less common in the US but underdiagnosed. Given the genetic relatedness of bartonella and brucella, in my experience it's not uncommon for brucella antibodies to be low positive or high negative in bartonella patients and may help diagnose bartonellosis even when the local testing for bartonella fails to do so. In such cases, specialized send out testing is available for bartonella which usually provides clarification. In my experience, some signs and symptoms which tend to be present predominantly in bartonellosis as opposed to Lyme include arthritis of the axial spine, which includes the sternum and sacroiliac joints, inflammatory arthritis of multiple joints in a 'rheumatoid arthritis' type presentation, breakaway weakness (sudden muscle weakness), myoclonus (jerking movements of large parts of the body), stretch marks,

uveitis and retinitis (inflammation of the front and rear of the eye, respectively), POTS (postural orthostatic tachycardia syndrome), an enlarged spleen, fevers, hemolysis (break down of red blood cells), low white blood cell count, low platelets (although this can happen in Lyme and other infections too), elevated hs-CRP (high sensitivity c reactive protein), which is a measurement of inflammation, and an elevated VEGF (vascular endothelial growth factor). It also sometimes causes a flare of symptoms in both the mornings and the late afternoons. Interestingly, brucellosis does the same thing to an even larger extent, so much so that one of brucellosis' many names is 'undulant fever', because every late afternoon the illness would get worse like a wave.

4. **Do you think I have Lyme or another tick-borne disease?** If I'm offering you antibiotics, then I believe that it's more likely than not that you have Lyme and/or another vector-borne illness. Until testing becomes foolproof, and it's very far from that now, these diagnoses are made clinically, which means based upon symptoms. Laboratory tests serve as support for the diagnosis, but the diagnosis doesn't hinge on the test in isolation. The presence of a herxheimer reaction can serve to further strengthen the diagnosis.
5. **Why tetracycline and not doxy?** I usually prefer tetracycline over doxycycline. The standard dose of tetracycline is over 7 times higher than the standard dose of doxy and surprisingly, doxy isn't materially stronger than tetracycline. In fact, tetracycline has been published to have some effect against B. burgdorferi persisters, whereas doxy has not, and studies of patients who have failed doxy have demonstrated that they can get better with tetra. Still, a minority of patients, most of whom have had bartonella in my experience, do better with other tetracycline class antibiotics such as doxy or minocycline rather than tetra. On the whole however, tetra usually seems to be better, plus it causes far less sunburn than doxy as well as less GI irritation per unit measure. Also, in adults and anyone over 8 years old it does not generally produce the vertigo, thyroid dysfunction, skin and tooth pigmentation which minocycline can produce.
6. **Why don't you use IV antibiotics?** I used IV ceftriaxone more in the first few years after having opened the practice in 1996, but soon realized that, on average, the results didn't seem to be better than those achieved with oral antibiotics, whereas the risks were higher. Published studies comparing IV ceftriaxone to doxycycline have demonstrated that IV ceftriaxone was not superior. These studies were performed in patients with positive spinal fluid tests for Lyme, meaning penetration of the infection into the central nervous system, which was historically the subgroup of patients in whom IV ceftriaxone was thought to have been necessary. In patients with chronic Lyme who have failed other treatments, IV ceftriaxone remains a reasonable option, but patients should realize that it's not a guaranteed cure for Lyme and that the risks are higher than those associated with oral antibiotics. If you are interested in taking IV

ceftriaxone through another provider, please ask us about our safety algorithm for its use. It's not uncommon for patients who are receiving IV ceftriaxone from another provider to see me to assist in safety monitoring and assessment of efficacy.

7. **Do you prescribe narcotics for pain?** No I don't, but I can prescribe non-narcotic pain medicines. If you still have severe pain which is not controlled by antibiotics, and requires pain management, it's best to see a pain specialist.
8. **What are persisters?** 'Persisters' is a term used for subpopulations of B. burgdorferi that survive against antibiotics in the test tube, such as doxycycline, amoxicillin, and ceftriaxone, which are recommended by some medical societies to treat Lyme. Tulane University, Northeastern University, and Johns Hopkins University, have all published research documenting that B. burgdorferi persisters survive the antibiotics that have long been thought to be curative by some doctors.
9. **If persisters survive, then how can Lyme be cured?** They're doing research on better combinations of antibiotics that have activity against persisters in the test tube and these would have to be studied in people. Northeastern University has shown that pulsed antibiotic therapy can kill persisters in the test tube. I've used pulsing, which means going on and off antibiotics at predetermined intervals, in my practice for many years and feel that it's very helpful in shortening antibiotic durations while increasing efficacy.
10. **What's a Herxheimer?** A Herxheimer is a flare of prior and/or new symptoms in association with beginning an antibiotic therapy in certain infections such as Lyme. They occur at different time points based on the drug used and the infection(s) present. They can range from mild to severe, and include an exacerbation of underlying symptoms as well as the development of new symptoms. Examples may include, but are not limited to, flu like symptoms, headaches, eye pain, muscle and joint pains, fatigue, sleep disturbance, tingling and numbness, and psychiatric symptoms. A Herxheimer is often described as a die-off reaction when the bacteria are being destroyed, but I believe that this is an oversimplification which is not entirely accurate. If this were the case, then how could a chronic Lyme patient have Herxheimer after Herxheimer over many treatment cycles? How many bacteria could there be in such a patient to cause so many repeated Herxheimers? Wouldn't they be destroyed already if that description were accurate? I believe that Herxheimers in chronic Lyme patients are due to the combination of a relatively small amount of bacterial destruction and a relatively larger amount of blebbing.
11. **What is blebbing?** Blebs are like microbial dandruff, or more aptly put, like decoys. They are small particles that are shed from the surface of both Lyme and bartonella. To the immune system, they appear the same as the intact organism. In the case of Lyme, they have been more researched, as there has been very little good research in

bartonella. (However, I consider it likely that the mechanisms demonstrated in Lyme blebs are similar in bartonella blebs.) They occur as part of a microbial stress response and induce immune dysfunction in the host by causing excess and abnormal stimulation which eventually results in anergy (failure of the immune system to properly recognize the infection). I believe that blebbing can occur during a Herxheimer and then again transiently upon discontinuation of the antibiotics. If blebbing does occur upon cessation of antibiotics, it provides clinical evidence that the infection is still present, even if symptoms subsequently settle down, which they usually do in about a week or so after blebbing begins. If taking pulsed antibiotic therapy, I believe it's best to wait until the blebbing has settled down before starting the next pulse of antibiotics, which is why I space the pulses 2-3 weeks apart, depending on the regimen and the respective half-lives of the antibiotics involved.

12. **If I have a herxheimer, when should I go to the ER and/or have you paged?** The following are all good reasons to go to the ER and/or page me but are not an exhaustive list, so use your best judgment: Fever over 100.5F without an obvious source, chest pain or shortness of breath, passing out, rash, bruising, bleeding from your bottom, significant nausea or any vomiting, watery, mucousy, or bloody diarrhea, hearing or vision loss, the worst headache of your life.
13. **What's 'brain fog'?** 'Brain fog' is an umbrella term defined differently by different patients. It's not a medical term, but more of a description of the fogginess that patients experience. Most patients complain of an unpleasant feeling of fullness, 'static' or 'cotton' in their head. Others describe it in terms of being easily distracted, as they might imagine ADD to feel, or a feeling of disassociation, disconnectedness or floating. Others describe feeling confused and/or complain of poor memory, which can range from mild to severe. Some report that brain fog causes them to feel anxious or panicked.
14. **Can I have more information on pulsed antibiotics?** Pulsing means going off and on antibiotics in a predetermined manner, rather than taking them continuously. Published research in the test tube with B. burgdorferi demonstrates that 1 application of ceftriaxone does not eliminate persisters, but that pulsed therapy does. Some published case reporting has described chronic Lyme responding to pulsed antibiotics when continuous treatment has failed. I tried pulse therapy many years ago due to the inordinate length of time it was taking to get my patients well with continuous antibiotic therapy, and in general, I find that it to be more effective. Not all antibiotics can be pulsed, some due to long half life issues and others due to increased risks of serious allergies and idiosyncratic reactions. Tetracycline is the backbone of many of my pulse regimens and is usually 2-3 weeks at time, depending on other antimicrobials in the pulse regimen. Of note, spirochetes such as B. burgdorferi, do not develop material

resistance to antimicrobials by their intermittent application. It's unknown if bartonella can but until proven otherwise I have to consider it possible. However, I've also used pulse therapy successfully in bartonella patients in cases where long term continuous antibiotics have failed. Remember, some antibiotics and antimicrobials are not pulsed. They include rifampin, bactrim, plaquenil (hydroxychloroquine), and Bicillin shots. If these are running out, you should either follow up in the office before they run out or get a refill.

15. **When do I make a follow up appointment?** It is best to schedule your next appointment with my secretary at the end of each appointment. Generally if you're on pulsed antibiotics, I'd like to have you follow up 2 weeks after therapy stops.
16. **Is there a charge for missed appointments?** Yes there is. Please make sure to call us with as much advance notice as possible if you can't keep an appointment. If you don't cancel with at least 24 hours notice, there will be a charge.
17. **How do I detox?** The term 'detox' as used in the chronic Lyme lexicon, has an alternative connotation and is not a traditional medical term. Everyone has a different idea of what it means. I think the basic tenet is that we're all trying to feel better and ease the suffering produced by these infections and their Herxheimers. Some patients report that herbals like parsley and burbur extract help them, as does liposomal glutathione or lemon water. In general, I think it can be helpful to eat a whole foods, anti-inflammatory diet, such a paleo or Dr. Weil's anti-inflammatory diet, as some patients report that it reduces symptoms. I also think it's important to induce a relaxation response to counter the stress response from these illnesses. Epsom salt baths can be helpful, as can gentle sauna, gentle massage, and gentle exercise. (Please note that I've seen large flares of symptoms after intensive sauna, intensive massage, and intensive exercise). I've also seen benefits to meditation and acupuncture. I also think it's important to eat warm foods, as this too induces relaxation.
18. **What herbals do I recommend?** Although I think herbals can be helpful, I usually try to hold off on additional variables when first starting antibiotics. This section needs a disclaimer because herbals are less well-studied than traditional Western medicine so I don't have a formal recommendation for their use. I provide this information as a service and suggest following-up with a naturopath or integrative medicine physician for further information. That said, I've seen many cases where they seemed to be beneficial. But they must be considered an unknown entity and treated as a medicine, meaning blood tests should be performed while on them to ensure that they are not producing a toxic side effect. I've seen abnormal liver function tests from herbals, even when patients were not taking antibiotics. Herbals that are published to be effective in the test tube against B. burgdorferi include grapefruit seed extract, banderol, samento, artemisinin, and stevia extract (the latter being from Nutramedix as it was specifically

mentioned in the article that this preparation worked better). For bartonella, herbals are largely anecdotal. Houttuynia is thought by many to work, and I believe that artemisinin is effective due to its mechanism of action and bartonella's affinity for iron and heme. There are special instructions and safety issues for artemisinin to be discussed before its use. Components contained in oil of oregano have also been published to be effective against brucella in the test tube. Since brucella is so closely related to bartonella, it's my assumption that this might have efficacy in the test tube against bartonella as well, but this is an unknown. It's also unknown if activity in the test tube for any of the herbals adequately translates to activity in the body.

19. **Will I get better?** Of course, It's not possible to predict the future, but the great majority of my patients rate themselves at better than 90% back to normal after treatment. The average duration of antibiotic therapy is usually about 6-9 months of antibiotics over about 9-12 months of time.
20. **What will the scope of my treatment look like?** Your initial treatment will be tailored to your needs at the time of the first office visit. Specifically, this is in regard to your symptoms, what you've taken in the past and how they worked or failed to work, as well as any limiting factors, such as if you've had stomach problems in the past. Subsequent rounds of treatment will be predicated on responses to the prior rounds and by your remaining symptoms, which should lessen over time. It is important to understand that healing from Lyme can feel like two steps forward, one step back. This is to be expected so please don't be discouraged. It's not my goal to offer false hope, but since most patients can get better, I don't want you to deny yourself the hope that you deserve.
21. **Will I relapse when antibiotics are stopped?** Many patients have recurrent symptoms between the first several pulses, which is to be expected. With continued pulses, most patients can go off antibiotics and be stable without them. A small minority of my patients have a chronic relapsing course after treatment. If your treatments are complete and you've gone off antibiotics but feel that symptoms are coming back, it's best to call the office and make an appointment for a re-evaluation.
22. **What do I do if the refill I requested isn't there?** Prescriptions from this office are sent electronically and in my experience about 1% of the time they don't go through due to an electronic blip even though they're listed as a verified transmission in our system. If you call the pharmacy just after it was sent over, sometimes the person answering the phone at the pharmacy may not have checked the incoming electronic prescriptions yet, so please ask that person to do so. If it's still not there, please call my office back immediately and have me paged if the office is closed and you are running out before the next day the office is open. If you're not running out before our next

open office day, just leave a message and we'll take care of it the next business day that we're open.

23. **When are you open?** The staff answers the phones Monday through Thursday, 9:30-3:00. Any calls after 3:00 will not be retrieved until the next business day. That means that if you call after 3:00 on Thursday, we won't be getting your routine message until Monday. The only way to get an urgent message through and receive a call back after hours is to page us. If you've paged us and haven't heard back within 1 hour, please page again and tell the service it's a second call and to make sure they've spoken to the person on call. All pages are returned as soon as possible, but cell coverage in this area is not great. In general, when in doubt, if it seems like an emergency, it's best to go to the nearest emergency room.