

Tick, Tick, Tick, TICK! The Truth About Lyme Disease (Part 1)

By: Martie Jacobson

You've just returned from a weekend of camping and wonderful trail riding, hunting, four-wheeling or hiking, shared with good friends. You've unpacked your vehicle and it's time for a hot, soothing shower.

As you're about to enter the shower you notice a deer tick attached behind your knee. You call to your spouse to bring the tweezers and he grasps the tick close to the skin, tugs and proudly proclaims he's removed the entire tick, including the head. It doesn't look very big, so you decide it hasn't been attached for very long, certainly not for that dangerous 24 hour period of which you've been warned. Just in case, you vow to check the site for the target rash you're sure will alert you to the possibility of Lyme Disease. Tick, Tick, Tick.

You check the site every day for a month. No target rash so you figure you're good to go. No worries. Tick, Tick, Tick.

But weeks after the bite, you experience flu-like symptoms of fatigue, fever, achy muscles and a headache. Just about the time you decide to see a doctor, the symptoms abate. You decide it was some sort of flu or virus which has run its course. Tick, Tick, Tick.

Gradually, over time, you begin to experience strange symptoms, perhaps joint pain, severe headaches, irregular heart beat or unbelievable fatigue. Months pass. You wonder what is happening to your body as you find yourself experiencing weird twitching of the face and other muscles, tingling, numbness, dizziness, intermittent nausea, difficulty concentrating, forgetfulness, poor short term memory and sensitivity to light. Tick, Tick, Tick, Tick.

You finally make an appointment with your doctor. A test for Lyme disease (pronounced "Lyme disease," not "Lyme's" disease) is one of several tests ordered by your doctor. It comes back negative and all other test results are normal as well. Although you are puzzled as to what is causing your various symptoms you breathe a sigh of relief. Save your breath ... you may need it because you just may have entered the nightmare of Late Stage or chronic Lyme disease. **Tick, Tick, Tick, Tick!**

False negative tests may occur if the test has poor sensitivity, is performed too early, antibody levels are too low to detect, or the bacterium has changed, which can limit the immune system's recognition of that bacterium. Unfortunately, according to many experts, testing for Lyme disease is only accurate 45 to 70% of the time, resulting in many false negative results. A few false positives also occur.

Ask to be tested for one or more of the following potential co-infections:

Babesiosis, Bartonellosis, and Anaplasmosis, These tick-borne diseases are often carried by the same deer tick which also carries the Lyme disease. Unfortunately, this means you very well may have Lyme, disease as well as one or more co-infections.

Doctors should not rely solely on tests but seriously consider your symptoms and medical history. If your doctor pooh-poohs your concerns, run, do not walk, to another doctor.

Your life may depend upon it. **Tick, Tick, Tick, Tick!**

Ten Facts About Lyme Disease: Supplied by the Lyme Disease Association, Inc.

1. Lyme is the most prevalent vector-borne disease in the U.S. and it's found in more than 65 countries world-wide.
2. According to the Centers of Disease Control & Prevention (CDC,) around 10% of Lyme disease cases meeting the CDC criteria are reported each year.
3. Patients with Lyme disease often have co-infections caused by Babesia, Anaplasma, Bartonella, or other organisms, clouding the diagnostic and treatment picture.
4. Lyme disease, the great imitator, can be misdiagnosed as MS, ALS, Lupus, Chronic Fatigue Syndrome, Fibromyalgia, Autism, Alzheimer's and Parkinson's.
5. A bite from a tick that's infected with Lyme disease bacteria can lead to neurologic, cardiac, arthritic and psychiatric manifestations in humans.
6. Children, ages 5 – 14 are at highest risk of acquiring Lyme disease. Some studies show significant IQ drops in students with Lyme disease that are reversed after treatment.
7. Lab tests for Lyme disease are not reliable; you can test negative and still have the disease.
8. Lyme disease can cross the placenta and may possibly cause birth defects or even death of the fetus.
9. A 2006 published CDC animal study shows that transmission of *Borrelia Burgdorferi* (the bacterium that causes Lyme) through blood transfusion in mice is possible.

10. A rash does not always occur with Lyme disease. According to CDC data, 30% of the reported surveillance cases lacked a rash. Symptoms may occur days or months after a tick bite & the tick does NOT necessarily have to be attached for 24 hours.

Lyme disease is the fastest growing epidemic in the world today and is much easier to treat when treated early. As mentioned earlier, according to some experts, current testing for Lyme disease is only accurate 45 – to 70% of the time, which means that approximately one half to two thirds of all patients with active Lyme disease receive false negative test results. And, as also mentioned earlier, there are also cases of false positives, too, depending upon the “bands” which test positive for Lyme. That’s a bit too technical to get into, but it does happen, so folks may be treated for Lyme without actually having it, which can be a problem, too. Because of this, a diagnosis of Lyme disease relies heavily upon clinical diagnosis. The International Lyme and Associated Disease Society (ILADS) reports that only 50 to 60% of patients recall a tick bite, a tell-tale rash is reported in only 35% to less than 60% percent and joint swelling typically occurs in only 20% to 30% percent of patients.

ILADS identifies itself as a nonprofit, international, multidisciplinary medical society, dedicated to the diagnosis and appropriate treatment of Lyme and its associated diseases. ILADS promotes understanding of tick-borne diseases through research and education and strongly supports physicians and other health care professionals dedicated to advancing the standard of care for Lyme and its associated diseases.

Top Ten Tips to Prevent Chronic or Late Stage Lyme Disease as published, in part, by the International Lyme and Associated Diseases Society.

1. **Know that Lyme disease is a nationwide problem.** Ticks known to carry Lyme disease have been identified in all 50 states and worldwide. It is not just the deer tick which carries Lyme and related diseases. Ticks are found wherever there is grass or vegetation. Spraying one’s clothes with DEET and Permethrin-containing insecticides (Permethrin is the key ingredient for repelling and killing ticks,) wearing long sleeves and long pants and tucking pants into socks continue to be the best ways to avoid ticks attaching to the skin. Always do a full body check after spending time outdoors.

2. **Check your tick facts.** Deer ticks can vary in size from poppy-seed sized nymphal (baby) ticks to sesame-seed sized adult ticks and can carry other infectious agents including Erlichia, Babesia and Bartonella. Lyme disease can be difficult if that's all you have, but even more difficult to treat if these other infections (co-infections) are present and they're not treated at the same time.
3. **Show your doctor every rash.** The bull's eye rash is the most common but there are many types of rashes (erythema migrans) associated with Lyme disease which can be mistaken for spider bites or skin infections. Take photos and see your doctor before the rash fades.
4. **Don't assume that you can't have Lyme disease if you don't have a rash.** Lyme disease is difficult to diagnose without a rash, Bell's palsy, arthritis, or meningitis but you can still have Lyme and not have any of those symptoms. Many patients experience indescribable fatigue, headaches, irritability, anxiety, crying, sleep disturbance, poor memory and concentration, chest pain, palpitations, lightheadedness, joint pain, numbness and tingling.
5. **Do NOT rely upon test results only.** Currently, there is no 100% reliable test to determine if someone has contracted Lyme disease or is cured of it. Physicians MUST consider a patient's symptoms, health history and exposure risks. Doctors experienced in recognizing Lyme disease will treat when typical symptoms are present, even without a positive test, in an attempt to prevent the development of chronic or Late Stage Lyme disease.
6. **Be aware of similar conditions.** Chronic Lyme disease is called the "great imitator" of our time because it is often misdiagnosed as other conditions such as Multiple Sclerosis, Fibromyalgia, chronic fatigue or anxiety. Ask your doctor to thoroughly evaluate you for Lyme disease, even if your tests are negative.
7. **"Wait and See" approach to treatment may be risky.** Up to 50% of deer ticks in Lyme-endemic areas are infected with Lyme or other tick-borne diseases. With odds like that, if you have high suspicion that you've been bitten by a deer tick, waiting to treat the disease has risks. An ounce of prevention really is worth a pound of cure with this disease.

8. **Don't be afraid to get a second opinion.** It is worth getting a second or third opinion if you are symptomatic and your doctor advises not to treat, or symptoms recur or persist after treatment. One symptom, perhaps a swollen knee, may not be seen as one part of a much bigger condition.
9. **Know your treatment options.** Work with your doctor not only in identifying and treating Lyme, but also to make sure that you don't have something else.
10. **Expect success.** You should expect to get better. Do not accept the "watch and wait" practice of stopping antibiotic treatment before you are well and then waiting for symptoms to clear of their own accord.

Finding a doctor who has knowledge of symptoms, diagnosis and treatment of Lyme disease may prove to be difficult. This is due, in part, because some doctors do not believe in long-term antibiotic therapy. However, that makes no sense to this author when that belief is in direct conflict with typical, long-term antibiotic treatment of other diseases such as Tuberculosis (TB.) Treatment for TB can go on for two or more years and is proven to work. HIV requires life-long treatment. Even chronic acne can require years of antibiotic treatment but acne doesn't kill you like some of the very serious, above referenced diseases do.

Ask any Late Stage Lyme disease patient which of two choices are preferable ... endure the debilitating symptoms of Late Stage Lyme disease, which can lead to multi-system involvement and even death, or undergo long-term antibiotic therapy which often goes unpaid by insurance and can cost the patient six figure amounts in some of the most difficult cases. Many families are financially destroyed while trying to pay for treatment of this disease, yet they do choose treatment when faced with seizures, dementia, immobility, feeding tubes, loss of bladder and bowel control, loss of balance, and basically, loss of a normal life for themselves and for those who love them.

In summary, if you have ANY reason to believe you've been bitten by a deer tick seek medical attention immediately. **Tick, Tick, Tick, Tick!**

Anyone can get Lyme disease. This author's 87 year old mother-in-law was diagnosed with Lyme last year and the only outdoor activity in which she participates is to water her patio flowers daily. Those of us who spend the greater portion of our time

trail riding, walking through pastures, camping, hiking, walking our dogs or hunting are at MUCH greater risk than those who do not. Also, if your dog or cats are house pets, they very well may bring in the disease-causing deer tick, which may decide YOU are a better victim than your pet.

It's not only dogs or cats which can expose you to disease carrying deer ticks, it can also be common while participating in equine events, so the following is directed toward our animal and equine friends.

Not too long ago, while participating with one of my horses at the Minnesota Horse Expo in St. Paul, Minnesota, I was appalled to hear the following from a friend of mine. A respected equine veterinarian from Minnesota, whom shall remain un-named, actually told my friend that Lyme disease symptoms do not exist in horses. After picking my jaw up off the floor, I asked her if she was sure she had understood him correctly. She assured me that, yes, he absolutely had firmly stated that Lyme disease symptoms do NOT occur in equines.

What I'd like to ask this particular veterinarian is, why then, can a horse test positive for the disease and respond to the correct course of antibiotic treatment in the same way that a human does? And why would a horse not succumb to infection, and all of its symptoms, with the Lyme disease causing bacteria as do dogs, cats, mice or other mammals? What would make the horse any different? His statement absolutely makes no sense whatsoever.

I'd like him to explain why my Shetland pony, Faith, tested positive for Lyme disease and ended up having to be euthanized due to becoming so ill and crippled up that the only loving thing to do was to put her out of her misery. Faith was originally diagnosed with laminitis even though her symptoms were not specific to laminitis other than a reluctance to walk. She tested negative for Lyme disease at first but after insisting she be tested again, we received a positive result the second time. This was a working pony with which I competed in harness events, both winter and summer, so she was not fat, which often alerts one to laminitis. I believe the reason she was first diagnosed with laminitis was simply because she was a pony and ponies often do get laminitis. But typically, those are fat ponies, allowed to overgraze with little to no exercise. Faith was fit and sleek. Nearing the time of euthanasia, her joints had become swollen and hot and she

could barely walk. If I had known then what I know now, I would have demanded the proper antibiotics and treatment and perhaps my little friend would still be greeting me with her soft nicker every morning as she used to.

Because Lyme disease and its treatment are often as misunderstood in animals as in humans the journey is not easy, nor is the cure quick or necessarily permanent. Because I am not a veterinarian I can only speak from my own experience.

I live in Southern Itasca County in northern Minnesota and have four dogs, three of whom have been diagnosed with Lyme disease. One, an English setter who is a working bird dog, has never been the same. The Cairn Terrier has painful muscle spasms and went from being a very happy dog to an irritable dog. The Great Dane also has Lyme disease. All three are treated symptomatically. All three of these dogs had been vaccinated with the Lyme vaccine, all wear tick collars and all are treated with Advantix every month, yet ALL have tested positive for Lyme disease and display the typical symptoms.

My Tennessee Walking Horse filly was diagnosed with Erlichiosis (a tick-borne disease) at age seven months. The initial signs were very subtle. The filly was just a little off her feed. I was scheduled to go out of state for several days so I called my vet and said I wanted her to be boarded at the clinic, "just in case she gets worse." She didn't have a fever ... it was just a gut feeling on my part. I took her in Sunday evening knowing my vet thought I was overreacting. She had no fever, just a different look in her eyes. By 3 p.m. the following day she'd developed a fever in excess of 106 degrees and was down in the stall at the equine hospital. The vet had immediately put her on IV antibiotics and anti-febrile medications after drawing blood. He wasn't sure if she was going to make it. He told me if I'd not brought her in because of my "gut feeling" she'd have died. She was hospitalized and on IV antibiotics for two and one-half very long weeks. She came home on oral antibiotics, thin as a rail, but alive and symptom free. She is now five years old and a very successful, national champion show horse. Hopefully, we caught it in time and she will continue to be fine.

My 10 year old Tennessee Walking Horse mare, Silk, was diagnosed with Erlichiosis the summer of 2009. Silk is the alpha mare in my herd, the last to lie down in the pasture, never wanting to give up her power over the herd. I had just finished the

morning chores when I glanced out to the pasture and noticed she was lying down while all the other horses grazed around her. I knew immediately that something was wrong. I brought her in, took her temperature and found it to be 103. Because of my earlier experience with my filly I was alert to any symptoms and caught it early. She was put on a regimen of Doxycycline. I took 50 capsules apart twice a day to mix the powder in with applesauce and Karo syrup to squirt into her mouth. It was a long three weeks. Silk seems to be fine, and I think I caught it early enough, but only time will tell. Both horses' initial symptoms were very subtle, both horses just "didn't seem right." Pay attention to your gut feelings. Be watchful. When in doubt, call your vet.

Every Spring I now give all of my horses two doses of Lyme vaccine designated for dogs. There are no guarantees, no studies showing it may prevent, but it sure can't hurt. I also use powder for livestock which contains Permethrin. This powder can be purchased in any livestock or feed supply store. Permethrin KILLS ticks and lice on contact, doesn't just repel them. I wear rubber gloves and a mask and rub it into their lower legs up to their hocks and knees and also on the lower third of their tails. I only do this once a week or so because you can over use it. I wish I could put it on their noses for grazing, but that's just too dangerous in my opinion. I also make sure I check the end of the spine in their tails. Ticks LOVE that area after climbing up the tail hairs. I know that the Permethrin containing powder works because I have one horse with four white stockings. Before I started using this product I would come home after riding and his white socks would be swarming with deer ticks. When I use this, I find no ticks. Again, I only use it once a week or so because it seems to hold up to water and sweat. I also keep my pastures mowed fairly short because ticks don't like sunlight which dries them out. Another thing I've done is to put my pasture fences approximately 20 to thirty feet away from the forest, thereby creating a perimeter which we keep mowed as well.

For you dog lovers Advantix is one of the few tick KILLERS that I know of. You don't want to just repel ticks; you want to kill the nasty creatures. I urge you to search on line for websites devoted to prevention and treatment of Lyme disease in animals. I typed in the words, "Lyme Disease Animals," and websites abound. Also, use your head. If something makes sense, then it's probably good information. If it doesn't seem to make sense, then it's probably not good information. If it sounds too good to be true,

it probably is. Listen to your instincts. Protect your beloved animals and don't let any veterinarian let you think you're overreacting. If I had succumbed to that I don't believe my coming five year old mare would be alive today.

Educate yourself to protect yourself against tick-borne diseases!!

Resources for Lyme disease Information:

The International Lyme and Associated Diseases Society: www.ilads.org

Minnesota Lyme Association: www.mnlyme.com

Lyme Disease Association: www.lymediseaseassociation.org

Lyme Info: www.lymeinfo.net

Minnesota Online Lyme Support: <http://health.groups.yahoo.com/group/minnesotalyme>

If you remove a tick which has potentially fed (contains blood,) stick it on to some tape, abdomen facing the tape and take it to your doctor for identification.

May is National Lyme disease Awareness Month. Walk-run events will be held in most states in May. For more information or to participate, please do an online search for the Lyme disease association in your state. You are encouraged to hang "Lyme" green ribbons from your trees, mail boxes, homes and businesses and to also wear "Lyme" green ribbons to help create awareness of Lyme disease. *Although May is officially National Lyme disease Awareness Month make EVERY month Lyme disease Awareness*

Martie Jacobson is a free-lance writer diagnosed with Lyme disease through a positive blood test. She has Late Stage Lyme disease and has had Lyme disease for at least 18 years which had been misdiagnosed as Rheumatoid arthritis. She lives in Itasca County in Minnesota. Her 32 year old daughter, Elizabeth, is wheelchair bound with Late Stage Lyme disease, plus four other co-infections. Elizabeth has been misdiagnosed for 26 years. Elizabeth's 3 year old daughter also has Lyme disease, probably acquired in utero according to more than one Lyme speciality doctor. Elizabeth lives in Little Falls, Minnesota. To read Elizabeth's story and for access to informational links go to: <http://www.caringbridge.org/visit/elizabethfadling>. Martie may be reached at mlj@2z.net. She wishes to acknowledge and thank all of the above listed resources for information included within this article.