

LYME DISEASE: PREVENT IT! ... OR DIAGNOSE IT AND TREAT IT EARLY. By Bonnie Ross. Dear Friends and Strafford Residents. I have long wanted to write about the serious nature of Lyme disease but have been unable to do so. I am thankfully experiencing some improvement with extensive IV antibiotics, etc. I write because I want you to be informed about Lyme disease. I'll mainly quote from various sources and provide you with a list of resources.

“Lyme Disease (LD) is a bacterial infection most commonly contracted from a tick bite that may initially cause a flu-like sickness. Untreated, or inadequately treated, it may cause long-term, persistent illness that can affect many systems of the body. Other tick-borne diseases are often contracted at the same time.” ... “Untreated LD can result in neurological disorders, crippling arthritis, blindness, deafness, psychiatric disorders, or death.” ... Relapses do occur.” Co-infections such as babesiosis, a red cell parasite ... “can be life-threatening.” Symptoms vary widely and can change with time. The good news is that if you have symptoms, you can diagnose it early and treat it with oral antibiotics and have no lasting problems!

Better yet, you can avoid getting the disease altogether. Deer Ticks feed the heaviest during late summer, fall and even early winter! They are the size of a poppy seed and nymphs are miniscule. So I advise, at very least, wearing socks over your pant legs when walking in the woods or tall grass. Long sleeves with elastic bands around the wrist are also helpful. The resources I list provide other suggestions.

Local doctors usually follow infectious disease guidelines that I believe are seriously flawed. I copied and pasted the beginning of a significant press release: “Thursday, May 1, 2008.... [CT] Attorney General Richard Blumenthal today announced that his antitrust investigation has uncovered serious flaws in the Infectious Diseases Society of America’s (IDSA) process for writing its 2006 Lyme disease guidelines and the IDSA has agreed to reassess them with the assistance of an outside arbiter [medical ethicist]. The IDSA guidelines have sweeping and significant impacts on Lyme disease medical care. They are commonly applied by insurance companies in restricting coverage for long-term antibiotic treatment or other medical care and also strongly influence physician treatment decisions. Insurance companies have denied coverage for long-term antibiotic treatment relying on these guidelines as justification. The guidelines are also widely cited for conclusions that chronic Lyme disease is nonexistent.” To read the complete version you can find it on line at: [www.ctlymedisease.org.featurearticle03.htm](http://www.ctlymedisease.org.featurearticle03.htm)

After a few months of being ill, my PCP agreed to put me on 10 days of Biaxin. I was amazed to feel remarkably better. Shortly later all my symptoms returned. Local Infectious Disease doctors said I did not have Lyme disease. I went without further antibiotics for 3½ years and my symptoms increased. I now see a Lyme literate MD in NY. While I contracted Lyme disease in an endemic area of Deer Isle Maine, Lyme disease and co-infections are now definitely present and rising in occurrence in Vermont. I have heard that Alice Peck Day doctors are more willing, than some local doctors, to provide a 30 day round of oral Doxycycline when Lyme Disease is suspected. I agree that inappropriate use of antibiotics is a valid concern, but “in the case of Lyme disease, the benefits of early and appropriate treatment far outweigh the risks”.

It is said of Lyme disease, “Like Syphilis, it is the great imitator” . I think that the following excerpt from a long letter, written by my Lyme MD, provides some interesting information that I'll share with you: “She has a history of a known tick bite accompanied by a circular rash in August 2003, followed by the onset of symptoms in December 2003. At the time of her visit to our office she presented with extensive symptoms ... please note that the diagnosis of Lyme disease is a clinical one which may or may not be confirmed by serology. Many Lyme sufferers do not test positive, but do have the clinical symptoms for diagnosis, and respond to treatment. However, Bonnie Ross has not only the symptoms

but also the positive test results described above. Diagnoses of Borreliosis, Bartonella, and Babesiosis have all been confirmed by serology from specialty laboratories...” Despite this and other MD letters, IV antibiotic treatment was denied beyond one month, by our insurance company, due to their claim that such treatment “is experimental.”

To learn about Lyme Disease, one needs to go to multiple resources. Here are resources that helped me: [www.ilads.org](http://www.ilads.org) (the largest medical organization devoted to tick-borne diseases) I highly recommend their “Advanced Topics in Lyme Disease”, if you need treatment.

[www.LymePa.org](http://www.LymePa.org) (“Lyme disease and associated diseases – The Basics” is worth printing out.)

[www.vermontlyme.org](http://www.vermontlyme.org) (a source of information and you can e-mail questions and gain contacts.)

[www.Lymeinfo.net](http://www.Lymeinfo.net) (patients page is good to read first [www.lymeinfo.net/patients.html](http://www.lymeinfo.net/patients.html)).

[www.LymeDiseaseAssociation.org](http://www.LymeDiseaseAssociation.org) (general information, recommendation of Lyme Literate Doctors and recommendation of Labs. I used IGenex, Fry, and MDL.)

Books: Cure Unknown: Inside the Lyme Epidemic by Pamela Weintroub and Coping with Lyme Disease, by Denise Lang

I miss being out and about in Strafford. This is such a special community. I miss the simple conversations at Coburns and the community involvement. You may see me out walking. Thankfully I am now able to do so and it is an essential part of my protocol. I’d like to share two symptoms because I want you to understand why I don’t stop to say hello while walking - orthostatic intolerance (being upright without moving causes blood pressure to drop significantly) and hyperacusis (sound intolerance) and in my case especially with speech, In general for me to listen, without other complications arising, I need speech to be extremely slow and succinct. I realize how difficult that is for most people. Just seeing you is a joy! Thank you for your generous hearts.