

Medical Ethics and the Discriminatory Treatment of Lyme Disease.

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HOW SICK will we have to become before the medical community and legislators of Vermont acknowledges that Lyme disease exists? How many children, men, women and animals are currently, or will become infected, with out knowing or be lulled into a false sense of security that the “Doxy”-cycline dosage administered was accurate and or even appropriate for the treatment of an embedded tick? Or even the fact that many medical practitioners will not prescribe antibiotics until they see symptoms. How many more “false negative” tests will there be with the current and antiquated two tiered test that has a 56% false-negative result! This fact alone would be inexcusable for any other disease!

The controversy over the long term administration of antibiotics for chronic Lyme disease is pure medical discrimination. IF we had any other illness or disease the medical community and pharmaceutical manufactures would be more than happy to pump us full of noxious chemicals and poisons for as long as *the medical experts* deemed fit. If we had tuberculosis or a host of other known bacterial infections, there would be several months of antibiotic therapy as standard treatment. Yes, there is a concern about MRSA and C-diff, or “Super Bugs” that are antibiotic resistant due to the over use of antibiotics. Let me state the obvious: doctors have over prescribed antibiotics to every child and adult with an ear ache or sore throat for the past 40 years, not knowing if the ailments were bacterial or viral. All livestock, be it dairy, meat or eggs, that we ingest have been pumped full of antibiotics for years. Is that *our* fault or problem? Is this why we are not allowed access to the proper treatment for a life-threatening bacterial infection? And WHY are medical review boards all over the country going after the few highly specialized LYME LITERATE DOCTORS who know how to treat this illness? This is a witch hunt. And I know of no other disease that faces this type of discriminatory practice.

Here are the big issues: currently, the two tiered Elisa and Western Blot tests, recommended by the CDC, do not screen, or test for, the many reactive bands that would show a positive bacterial infection. These tests only screens for five bands for an IgM, and 10 bands for an IgG. Respectively, two out of three bands must show reactivity and five out of ten bands must show positive or sensitivity for a positive test. However, if there is reactivity under the prescribed number of bands, then you don't have Lyme, according to the CDC. There are as many as 25 or more reactive bands or antigens that should be tested for sensitivity. But, because they are only testing for a few bands, hence the 56% false negative inaccurate results. New tests that are accurate are expensive and not covered by insurance companies. I had many, *gold standard*, Elisa's and Western blots test for over 16 years that never showed enough reactivity for Lyme, henceforth, I was told over and over again that I did not have Lyme. Well, I did and do...thank you!

Secondly, attitudes in the medical community about the treatment of Lyme and the existence of Chronic or Latent Lyme need to change so the seriousness of this illness, if left untreated or treated improperly, is realized. Guidelines for the treatment of Lyme need to be revised by the IDSA, (Infectious Disease Society of America), and all medical practitioners need to know the signs and symptoms, proper testing, and treatment. Guidelines for treatment through the International Lyme and Associated Disease Society, or ILADS, are a better resource and are more accurate in understanding the challenges of identifying and treating this illness than the IDSA guidelines.

There are three forms of spirochete bacterial infections: first, the Spirochete: very mobile, capable of penetrating dense tissues and bones, and capable of intracellular infection. If treated improperly, it rapidly converts to a “Cell Wall Deficient” (CWD) form, which makes targeting by the immune system and use of antibiotics much more difficult. Symptoms may include, a Bull’s eye rash, (less than 1/3 of the tick bites exhibit the rash), Bell’s palsy, flu like symptoms, fever, fatigue and wandering joint and muscle pain. Once the bacterium has moved into CWD form, it causes the body’s own immune system to convert Vit D into immuno-suppressive hormone known as 1.25-D, causing autoimmunity. The bacteria then clump into dense colonies-inner layers unreachable by antibiotic and the immune system. Symptoms at this stage often mimic numerous syndromes such as paralysis, multiple sclerosis, mental disorders, (depression and brain fog), chronic fatigue, neurological conditions, post Lyme syndrome, Alzheimer’s, and Parkinson’s. That is why it is known as “The Great Imitator”. The “cyst” form is when the bacteria are dormant and immobile, without overt symptoms, until the immune system has a stressful event, be it emotional, or physical such as trauma or even heavy metal toxicity, or exposures to molds and toxins, and re-infection. At this stage, Lyme is most difficult to treat because the bacteria can survive antibiotics, starvation, pH changes, hydrogen peroxide, temperature variations, and most other adverse conditions. It is imperative that one uses the proper protocol and enzymes to open and break down the cysts or bio-films, so antibiotics can kill the bacteria. This type of specialized knowledge may only come from a Lyme Literate physician, not just any doctor or neurologist. As with all illness, it takes individualized approaches and treatments based on the response of the individual. Not one size fits all. This is a Multi-Systemic Auto-Immune Disorder or MSAID.

According to Eva Sapi, a leading Lyme researcher testing the efficacy of Doxy and Amoxicillin on spirochete bacterium, discovered while the Doxy decreased the bacterial load by 90%, it increased cyst levels by 200%! Doxy inhibits protein synthesis--it kills bacteria, including Lyme by action within the cytoplasm, inhibiting the manufacture of proteins required for the bacteria’s survival. However, when testing the efficacy of Amoxicillin, it killed 90% of the spirochete forms, but also killed 68% of the cystic forms. So much of what was thought to be known as accurate is not with this illness.

IF this is the case, and the attitudes and belief by the medical community is that once you have been treated, you are cured, and even though you will always exhibit as Lyme positive, the American Red Cross doesn't screen the blood for Lyme disease or other Tick Borne Illnesses. Yes, they ask you if you have had the illness and if you have been treated, and believe that once you have been treated, the blood products are safe. However, the bacteria may go dormant and can hide in the body and later become re-activated when the environment is optimal. They do screen for the follow infectious disease: Anti-Trypanosoma cruzi, Hepatitis B & C, Human Immuno-deficient Viruses type 1 & 2, Human T-Lymphotropic virus, Syphilis, and West Nile. And we now know that Lyme disease comes with an entire host of other bacteria's or Tick Borne Illnesses, known as co-infections, i.e., Babesia, Erlichia, Bartonella, Mycoplasma, Chlamydia, Rickettsial Infections and or Q Fever. And there is a new emerging Lyme bacterium from Japan, known as *Borrelia miyamoto*, a super virulent strain, already found in the state.

NOW let's look at the real tragedy of this illness and how it takes its toll on the health of the population with its horrific symptoms, causing the inability to work, and sometimes death or suicide. But, here is what the medical community and legislators need to realize: according to a CDC report from 2011, canine serology has been identified as a sensitive marker of human risk.

Holly Ahern, PhD. (2013) produced an Econometric extrapolation formula of human risk of Lyme disease based on the percentage of canine infection in the state. In 2012, sixteen percent (16%) of the canine serology had tested positive for Lyme in the state of Vermont. Vermont population of 2012 was 626,011. Sixteen percent of that population is: 100,162. That is potentially how many people may be infected with Lyme bacteria and co-infections as of 2012.

The CDC's current estimation of cost of treatment per Lyme infected individual is: \$9,888.00. And that is just for the standard treatment. I personally have spent over \$45,000 out of pocket for treatment not covered by insurance companies, and I know many people who have spent hundreds of thousands of dollars of their own money, seeking out one specialist to another, desperately trying to get better.

Okay, let's extrapolate: $100,162 \times \$9,888 = \$990,401,856$. Thus the financial burden of untreated or improper treatment of Lyme disease to the state of Vermont is almost a **billion dollars**. Should we look at the amount of lost tax revenues that the state won't receive due to the fact that many of the people infected with Lyme can not work? How about the disability payments that the state must award these folks? The financial cost or burden to the state is many times more than stated. One would think that these statistics alone would get the attention of the state!

Why is one illness that is of epidemic proportions throughout the state not being recognized or treated fairly? Why is the medical community and ethic boards denying us proper treatment and Lyme Literate Doctors? Why is it that our *elected* state legislators, particularly the Health Care Committee have denied us, year after year, a Healthcare Protection Bill to protect our Lyme Literate Doctors from being sought after by the medical review board? The following states have passed or have introduced a bill that is pending: California, Connecticut, Delaware, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Pennsylvania, Rhode Island, and Washington, DC. Notice that every state mentioned other than California, is in the NE corridor where Lyme disease is of epidemic proportions. Why is Vermont, which has the second highest infection rate in the country, ignoring the importance of passing a Lyme Protection Bill?

All we ask is that we are treated properly and fairly, without discrimination and that our special Lyme Literate Doctors are protected from the medical review board for treating Lyme patients. How many people have to become seriously ill or die before the medical community and our state representatives, whom we elect, really care?