

THREE ANECDOTAL CASE REPORTS REGARDING CHRONIC LYME DISEASE WITH A HYPOTHESIS THAT MIGHT EXPLAIN HOW THEY CAME ABOUT *

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Introduction

Professor Teddo Adderatti of the medical school in Bolgna Italy introduced case reports as a medical teaching tool in the mid-thirteenth century. Although they have fallen into some disrepute due to present feelings about the lack of importance of anecdotal evidence, they still can be seen in many prestigious medical journals.

The Jewish King Solomon who lived in the tenth century B.C. is credited by some for the biblical quote “there is nothing new under the sun-what happens will happen again.” It is in these contexts these three reports and a hypothesis that might explain them is being presented.

Case One: The patient is a 63-year old retired male science teacher who spent his summers in a farm in Wisconsin that was in an area known to be infested with deer ticks. At age 55 he developed a progressive syndrome that consisted of generalized muscle cramping and spasm. Over the next 4 years these symptoms grew to include severe fatigue, difficulty in concentration, neuropathic numbness and pain both of this feet and severe testicular pain. Low body temperature, generalized fasciculations over his torso and extremities and an unexplained sudden central retinal vein occlusion in his left eye.

During the ensuing six years after the onset of the syndrome all of the symptoms gradually increased until they came to the point that he could no longer function. Visits to many physicians and specialty clinics failed to provide an explanation for this clinical picture.

He searched the web and came to the conclusion that he might have Lyme disease. He consulted me in this regard in April of 2005 and I agreed that this was a possibility. HE agreed to my suggestion that we try an empirical course of intravenous Ceftriaxone to see if it helped him. Prior to the antibiotic regimen, the patient was tested for Lyme disease by Western Blot test performed by Igenex Laboratories. These results were suggestive but not conclusive for the presence of Lyme disease. He also underwent an experimental Lyme test performed by Bowen Labs of Florida. This test strongly indicated Lyme infection.

Accordingly, he was given an eight-week course of intravenous Ceftriaxone and Flagyl. The Flagyl was given to help his gastrointestinal tract tolerate the Ceftriaxone and for the theoretical concept that Flagyl might kill cystic forms of Borrelia. The Flagyl was

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discontinued when it seemed to increase the neuropathic pain and numbness in his feet and legs. He suffered no Herxheimer reaction but made gradual improvement during the initial program. After the Ceftriaxone he was maintained on 3000 mg of oral penicillin daily for three weeks followed by 50 days of 200 mg of Diflucan. This regimen of penicillin followed by Diflucan was repeated one additional time. His improvement continued and within weeks he was essentially asymptomatic. The oral antibiotic treatment was complete in January of 2006. Additionally, in January of 2007 Mr. C. was put on a daily course of low dose Naltrexone (4.5 mg daily). Mr. C. reported that this greatly decreased the occasional return of fatigue, depression and testicular and neuropathic pain. In December 2007 he felt well and was functioning normally.

Case 2: This highly intelligent and active registered nurse was 50 years old when in 1992 she suffered a tick bite that was followed by a bull's eye rash and a positive blood test for Lyme disease. She was treated for 10 days with doxycycline. She was told that this cured her Lyme disease. She lived in Minnesota in an area known to have deer ticks.

Several months after the 1992 incident she developed a progressive symptom complex that included severe fatigue, muscle weakness and episodes that suggested to some narcolepsy and to others a mysterious virus. During the ensuing ten years all symptoms increased and the physicians she consulted could not find an explanation for them.

She saw me in 2002 with a chief complaint of severe debilitating chronic fatigue. She had come to the conclusion that she had this syndrome after she looked it up on the Internet and made a self-diagnosis of Lyme disease. She had never mentioned the fact that she had had Lyme disease to her doctors nor had she ever been asked about this disease. She had accepted the original opinion that she had been cured. After hearing her entire story, I concluded that while indeed she was chronically fatigued that something else was wrong.

Knowing that she came from Minnesota in an area in which deer ticks were present, my first question to her was whether she had been exposed to tick bites. She told me about her case of Lyme disease in 1992. After the initial preliminary tests were done and were normal I suggested to her that she might have chronic Lyme disease. I suggested an empirical treatment program tailored to not only treat the Lyme disease but to treat her chronic fatigue in spite of the fact, that all tests for Lyme disease were negative.

I suggested this because she shared with me "she had reached the limit of her endurance". The program consisted of the following:

1. Ceftriaxone, 4 grams given intravenously through a PIC line for 4 weeks
2. Flagyl, 500 mgs daily to be taken by mouth. This was to help her tolerate the Ceftriaxone bowel-wise and also to treat the theoretical cystic forms of *Borrelia* which some think will be effective in this regard
3. To treat her fatigue, Gamma Globulin 4cc i.m., twice a week for 4 weeks, to perhaps provide some blocking antibodies that would inhibit autoimmunity
4. Isoprinosine, 50 mgs by mouth four times a day to stimulate T-cells

5. Valtrex, 1000 mgs, twice a day by mouth to treat the Epstein Barr virus which I felt might be involved in her disease (see the hypothesis that follows the case reports)

When there seemed to be a marked salutatory response of her entire symptom complex we continued the oral and intra muscular elements on an intermittent basis. There was marked gradual improvement in all her symptom complex starting after the intravenous Ceftriaxone. This continued as we tapered the medication over the next four years. A complete examination in January 2008 revealed that she was symptom-free and living a very busy productive life. This consisted of taking care of her three children and running programs dedicated to the care of foster children who had developmental problems.

Case 3-AR; A case of chronic Lyme disease that mimicked multiple sclerosis

This case is another incidence of the truth of the biblical saying “there is nothing new under the sun. What happens once will happen again.” Soon after I had finished bringing up to date this website a young physical therapist who had two small children presented her self for an examination with the following story: I will present it in her own words, modifying only her feelings about the delay in diagnosis and treatment. *“I am a physical therapist. I know my body. I was healthy and fit until June 9, 2007 when I attended an outdoor party in Richmond, Illinois. A day after the party, I noticed a red, circular rash about the size of a quarter on my lower right abdomen. I knew immediately this bite was different than the typical bug bit—it was angrier looking, and had a distinctly defined center. I immediately thought of Lyme disease. But everyone I knew who lived in Richmond and all the medical professionals I knew, said no way. It couldn’t be Lyme disease. They had never heard of it in Richmond, or Illinois for that matter. So I put it out of my mind.*

About four days later I suddenly felt very sick, faint and out of it. I had several bouts of diarrhea. My husband rushed to my side and took me to see the obstetrician who had delivered my second baby four weeks before. He said the symptoms were probably nothing or blood poisoning. About the bite he said he had had one also on his arm, probably from a mosquito.

The feeling of being sick remained so a week later I saw an internist. He said I absolutely did not have Lyme disease because I hadn’t seen the tick and the tic would have ballooned up with blood to enormous size. He also said that there was no Lyme disease in our area. He did not advise treatment or studies. Then the muscle twitches began along with the strange traveling paresthesia. Then I noted electric type currents through my extremities and migrating joint pain.

I continued to seek help and saw two other physicians in my area. They empirically prescribed antibiotics but said that the blood tests that they had run were negative so I could not have Lyme disease. My symptoms continued and got worse, and then a brain fog set in. I couldn’t seem to concentrate. I felt mentally weighed down and fuzzy headed and mentally depressed and frightened.

I sought another internist who when my Lyme tests came back negative told me I couldn’t have Lyme disease and that I should discontinue the antibiotics. My symptoms remained. I began wondering if it’s not Lyme, then what is it? A pinched nerve, carpal tunnel, fibromyalgia, some progressive neurological disease? I was researching and

researching and still, the only thing that made any sense was Lyme. Eventually, and logically, my mind wandered towards MS. By this point, I had developed a positive l'hermettes sign. I referred myself to a chiropractor. I saw him 3 times and he was stumped. But we did discuss the possible justification for an MRI. So I didn't appear to be a hypochondriac, I referred myself to a neurologist at another one of Chicago's premier hospitals prior to requesting any MRI. This neurologist, I could tell somewhat reluctantly gave me the referral. The MRIs revealed the cause of many of my symptoms-4 white lesions, 2 in the brain and 2 in the cord. He then referred me for a lumbar puncture, which came back positive for antibodies to "something" and 2 oligoclonal bands. He diagnosed me with, most likely, relapsing-remitting MS. My "Lyme tests" were again negative. My family and I were crushed. We discussed beginning MS drugs. I soon thereafter had my first full-blown neurological event, partially brought on by the stress of this nightmare..diffuse numbness and muscle spasms, and ended up in the ER, and then in the hospital for a night.

The patient continued her search for help and more consideration of the possibility of her findings being due to Lyme disease and through this website decided to come to see me about her problems. Her history, the white lesions on her MRI, the picture of her tic bite that she showed me, her hyperreflexia, paresthesia, ataxia and absent abdominal reflexes convinced me that she had Lyme disease masquerading as multiple sclerosis. An empirical course of anti Lyme disease therapy was started through a "pic line." It consisted of a six week course 4 grams of intravenous Ceftriaxone and flagyl, 500 mgs given twice a day by mouth. She is being continued on oral doxycycline and erythromycin. Blood tests done at her first visit did come back suspicious for Lyme disease. They were done by Quest laboratories and confirmed by Bowen Laboratories. She also had antibodies against Bartonella Henselae and Bartonella Quintana which confirmed exposure to tics. Four months after the completion of the intravenous Ceftriaxone she describes her situation as follows:

"I complete a 6 week course of IV antibiotics, coupled with some oral medications and am now in my fourth month of treatment for chronic Lyme disease. I feel immeasurably better. My brain fog has completely cleared. I'm not tripping over my words or losing my train of thought anymore. MY paresthesias and muscle twitches are few and far between. My energy level is up. All in all, I feel almost back to normal and most definitely vindicated. And I'm now on a mission to educate others about this often misdiagnosed and mistreated disease. This is a "silent epidemic", as many like to call it. Had I listened to the highly regarded and overly confident neurologist who diagnosed me with MS I would now be much sicker, getting precisely the wrong treatment, and headed for more debility.

Comment: Of course a few anecdotes do not establish anything but each case of an unusual nature that presents itself to an inquiring physician should not be ignored. The third case buttresses my opinion that is outlined on this website that cases of MS-like nature that appear after tic exposure deserve an empirical course of Lyme treatment. Finally, it is to be noted that each of these three cases was self-referred after they had studied the Internet. They indicate that we all should listen carefully to patients who come in with reams of Internet material. Some, but certainly not all, may have been able to arrive at correct diagnoses.

A Hypothesis which might explain what happened to these three patients.

This hypothesis is based on the work of Westall and Root-Bernstein.* They proposed in the mid 1980s that an autoimmune disease can occur when a host is exposed to two chemically complementary antigens one of which exhibits molecular mimicry with the host tissues. In addition, the host must have a certain HLA pattern and an immunological adjunct must be present. They named their syndrome “multiple antigenic mediated autoimmunity”, the MAMA syndrome. Root-Bernstein proposed that this syndrome occurred in some AIDS patients because they were exposed to multiple viral and bacterial antigens. This exposure occurred because of their T-cell problems. I propose that the three patients described developed a MAMA syndrome because their Borrellia antigens were chemically complementary to the Epstein Barr virus to which they had had evidence of being exposed. That Epstein Barr virus shows molecular mimicry with human tissue was shown by Root-Bernstein. The immunologic adjunct necessary for this syndrome was provided by indigenous myramyl peptides produced by the host’s indigenous mononuclear cells. Finally, the initial clones stimulated by the MAMA syndrome became rogue clones and attacked tissues in addition to those involved in their being developed.

Discussion and conclusions: Certainly these anecdotal case reports do not prove anything. They are presented because of the large numbers of individuals who appear to be struggling with similar syndromes after they have been exposed to tic bites. This number seems to reveal itself when one takes even a cursory look at websites and chat rooms on the Internet.

*See the discussion about this syndrome and references in the section in this website on MS following Hepatitis B vaccination

Surely all of these concerned suffering individuals are not suffering from “extraordinary popular delusions and madness of crowds, so brilliantly described by Charles Makay in 1841.

It is my hope that the hypothesis presented here will stimulate interest in methods to help unfortunate individuals who suffer from chronic Lyme disease. It seems that the procedures described here may help some of these but if as I propose chronic Lyme disease has an autoimmune aspect attempts to treat this aspect empirically may be in order.

It would appear to me that intense consideration should be given to the possibility that multiple antigenic exposure can cause autoimmune disease because of the multitude of vaccines that are now being introduced into general use. The experiments that can be done to prove or disprove this hypothesis are presented later on pages on this website where we explain autoimmunity that occurs after vaccinations in a similar manner.