



lyme.kaiserpapers.org

**A Kaiser Papers
Public Service Page**



In Copyright Since September 11, 2000 This web site is in no manner affiliated with any Kaiser entity and the for profit Permanente Permission is granted to mirror this web site. Please acknowledge where the material was obtained.

Estimated reading time: 7 minutes

Contains 1414 words

Introduction

Lyme disease is a serious bacterial infection caused by *Borrelia burgdorferi*, a corkscrew-shaped bacterium of the spirochete group. Other spirochetes cause diseases such as syphilis, rat-bite fever and relapsing fever. The primary means of infection is by tick bite although the disease has also been shown to be transmitted by other insects. The nymphal Ixodes tick, the primary culprit in transmission, is so small (about the size of a poppyseed) the victim will rarely notice it and will not feel it bite. People should not be lulled into thinking themselves safe because they did not notice a tick. Maternal-fetal transmission of the Lyme disease spirochete has been demonstrated by a number of credible clinical studies by Lyme disease researchers. Sexual transmission of Lyme disease is suspected by leading clinical practitioners.

Because of the unreliability of most tests and laboratories, Lyme disease can be difficult to diagnose for those with no expertise. Inexperienced doctors tend to rely on highly restrictive CDC testing criteria that very few can meet – perhaps only 5% to 10% of those with proven Lyme disease that was never treated. They naively believe that if a person does not meet the strict and exclusionary CDC serodiagnostic criteria developed for surveillance purposes, that person does not have Lyme disease. Kaiser doctors have used this ploy as a means to support a non-diagnosis. The CDC has repeatedly stated that Lyme disease is a clinical diagnosis and that surveillance case standards should not be used for diagnostic purposes.

Most experienced doctors diagnose Lyme disease according to the cluster of symptoms it can present. These symptoms are stated in the articles within this section. The most common symptom associated with Lyme disease is fatigue. The “erythema migrans” rash is the only symptom specific to the disease but only occurs in 50% or fewer of those infected. It normally occurs within 30 days of infection and then fades. Late-stage Lyme disease victims often do not notice and do not recall a rash.

Kaiser’s Lack of Tick Borne Disease Expertise and Misdiagnoses

Kaiser does not seem to have any doctors experienced in tick borne diseases. The guidelines

they follow promote the view that Lyme disease as "hard to catch and easy to cure", despite the fact that the disease is epidemic in their market areas. Late-stage and chronic cases can involve long-term treatment and substantial expense. They also have not shown any demonstrated expertise, judging from our patient inputs, in diagnosing coinfections of Lyme disease and other infections which can be as devastating as Lyme disease. Complications of Lyme disease and tick-borne coinfections are often disabling and sometimes can be fatal.

Kaiser's usual reaction is to misdiagnose the patient with a syndrome of unknown case and unknown cure or to suggest a patient has psychiatric disorders. Or the member may simply be abandoned. Some of the more common misdiagnoses are chronic fatigue syndrome, fibromyalgia, multiple sclerosis, lupus and early Alzheimer's disease. If a well meaning Kaiser doctor tries to help a patient with advanced Lyme disease, that doctor is normally forced to defer to Kaiser's infectious disease doctors who will likely deny a diagnosis of Lyme disease.

Kaiser's Economic Rationale for Denials and Methods of Denial

An upper-level Kaiser employee explained to me why Kaiser will not help Lyme disease victims. This person, and the spouse of this person, both have chronic Lyme disease. They have to go to a non-Kaiser doctor for treatment and pay out-of-pocket. This person explained that Kaiser views Lyme disease in the same context as AIDS only that Lyme disease is far more common and the risk exposure far greater. AIDS has been and is a large cash drain for Kaiser and they don't want to repeat the experience. So their solution is not to diagnose in the first place or to severely limit Lyme diagnoses. This explanation is consistent with Kaiser's behavior – it's about money.

Kaiser has thus far managed to escape culpability by claiming to follow restrictive guidelines published by the Infectious Diseases Society of America (IDSA). The Connecticut Attorney General has launched an investigation into the monopolistic guidelines policy of IDSA and the "Lyme experts" who authored the IDSA guidelines. There are two standards of care for Lyme disease. Kaiser will not give the member the choice of following the guidelines issued by the International Lyme and Associated Diseases Society (ILADS) because the open-ended treatment could prove too costly.

Kaiser has gone one step farther than the IDSA guidelines in order to avoid diagnoses. West Coast patients have had their blood samples sent to the East Coast for analysis, a practice that has been condemned by IDSA because of the high risk of sample degradation.

According to laboratory records, in some cases samples were not analyzed for as long as two weeks after the blood draw, likely rendering the sample worthless. In other cases samples have been sent to the laboratory of Allen Steere (IDSA). Another factor is that the cheap and inaccurate Elisa "screening" test that Kaiser uses is based on an East Coast strain of the Lyme spirochete. Comparison with a reference strain that differs from the strains found on the West Coast will be more likely to produce a "negative" result. Kaiser has been known to dismiss test results from the highest rated laboratories in the country for tick borne infections, no matter how specific and how diagnostic the results may be.

One method used by ethically challenged HMO's and health insurers to discourage extended treatment is to file anonymous complaints to state medical boards against doctors who

“overdiagnose and overtreat” Lyme disease. In fact, Kaiser instigated one of the earliest cases of Lyme physician harassment in the United States by filing a complaint against an Oregon doctor who was diagnosing and treating Lyme patients, one of whom was a Kaiser member. Kaiser was “tipped off” to this physician when the patient attempted to fill a prescription for long-term antibiotics through a Kaiser pharmacy. Kaiser paid for an East Coast "Lyme expert" to testify before the Oregon Board of Medical Examiners on whom Kaiser appears to have an undue influence, not only in this case but other cases as well not involving Lyme disease. This “Lyme expert” is now part of the investigation by the Connecticut Attorney General.

The physician was told to stop treating Lyme patients or to give up his license. Since no physician has the resources to contest Kaiser’s legal and financial assets, he chose the former and was forced to give up his Lyme patients. This early case of Lyme physician harassment has had a very negative effect on the ability of Pacific Northwest residents to get help for Lyme disease since this threat has discouraged regional doctors to become specialists in tick borne diseases. The Pacific Northwest is also home to two ex-presidents of the Infectious Diseases Society of America, David Gilbert of the Oregon Health & Science University and Walter Stamm of the University of Washington, both of whom seem to do their utmost to insure that regional doctors comply with IDSA restrictions on treating Lyme disease.

Some states, including California, have adopted legislation to protect doctors treating Lyme disease.

Conclusions

A Kaiser member who suspects they have Lyme disease should seek help from a tick-borne disease specialist. Prompt and sufficient treatment is essential to prevent the disabling complications and probable incurability of a late-stage infection and a potential lifetime of misery. Undertreatment is a potentially dangerous option. Kaiser Lyme disease victims in Oregon and Washington normally go to California or the East Coast for competent treatment. Most tick-borne disease specialists on the West Coast are quite familiar with Kaiser members. East Coast Kaiser members have a number of excellent tick borne disease specialists available to them. As a former member of Kaiser for 27 years, I had to change health plans because three infectious disease specialists at Kaiser Permanente Northwest refused to diagnose me for Lyme disease despite specific serodiagnostic criteria and symptoms consistent with and diagnostic for Lyme disease. Two of these doctors never even saw me. At the time, I was in very poor health because of Lyme disease. It took four years of treatment by a tick borne disease specialist to regain most of my former health.

The loss of 10 potentially productive years – 6 years undiagnosed and 4 years in treatment - can never be compensated. It was the callousness, ignorance and dishonesty of these doctors and the subsequent knowledge that Lyme disease denials are standard operating procedure for Kaiser that prompted me to create this Lyme disease information page for Kaiser members. The refusal to diagnose Lyme disease by Kaiser doctors, particularly late-stage disease, seems to be quite common.

I hope the information on this page is helpful to those for whom it was intended and that those who read it are spared the negative and harmful experiences of myself and others regarding Kaiser and Lyme disease.

Miguel Perez-Lizano