

**H.R. # 6140 92 31**

**Pt. Name: Miguel A. Perez-Lizano**

**PATIENT COMPLAINT/REBUTTAL for inclusion in patient's medical record.**

**Date of Document: Unknown**

**Encounter date: June 5, 2000**

**Type of document: Outpatient progress notes.**

**Complaint & Rebuttal:**

**This complaint/rebuttal regarding the encounter with Dr. Steven J. Spindel and the medical report he filed relevant to this encounter. For the sake of brevity, I have limited this complaint to relatively few issues.**

**The defining moment of this encounter came after Dr Spindel left the room. My adult daughter, who was with me during the entire time and who rarely cries, was sitting in the corner of the room with tears running down her face. I asked her why she was crying. She replied, "You asked him for help so many times and each time he refused."**

**Dr. Spindel should be informed that incompetence, negligence, and making false statements to deny medical care constitute medical malpractice and health insurance fraud.**

**When I told Dr. Spindel that I would complain about his conduct during the encounter, he replied, "Good luck!"**

**Selected Issues:**

- 1) I presented with symptoms of Lyme disease consistent with the Centers for Disease Control (CDC) clinical guidelines. These symptoms are documented in my medical record and in the Chronology and Summary of Symptoms that I provided. Dr. Spindel refused to diagnose and treat me for Lyme disease despite what he agreed was endemic exposure.**

**Dr. Spindel failed to provide any differential diagnosis, failed to question me on anything that could provide any information for diagnosis, failed to suggest or provide referrals to specialists who could provide help, failed to order any laboratory tests which could provide diagnostic insights, and failed to take any action of any kind to help me.**

**In fact, when I asked Dr. Spindel if I didn't have Lyme disease, what did I have? He responded he "didn't want to debate."**

The Centers for Disease Control defines a clinical diagnosis of Lyme disease as follows:

**“Clinical description: Lyme disease most often presents with a characteristic “bull’s-eye” rash, erythema migrans, accompanied by non-specific symptoms such as fever, malaise, fatigue, headache, muscle aches (myalgia), and joint aches (arthralgia)...The signs of early disseminated infection usually occurs days to weeks after the appearance of a solitary erythema migrans lesion. In addition to multiple (secondary) erythema migrans lesions, early disseminated infection may be manifest as disease of the nervous system, the musculoskeletal system, or the heart...*B. burgdorferi* infection in the untreated or inadequately treated patient may progress to late disseminated Lyme disease...The most common objective manifestation of late disseminated Lyme disease is intermittent swelling and pain of one or a few joints, usually large weight-bearing joints such as the knee. Some patients develop chronic axonal polyneuropathy, or encephalopathy, the latter usually manifested by cognitive disorders, sleep disturbance, fatigue, and personality changes...Lyme disease morbidity may be severe, chronic, and disabling.”**

The CDC specifically, but not inclusively, also states as late-stage symptoms, **“nervous system problems including sleep difficulty, problems with memory, coordination, and concentration, dizziness and irregular heartbeat, joint pain, stiffness...”**

Almost all of these symptoms I had and were clearly stated in the documentation I provided to Dr. Spindel or documented in my medical history.

- 2) At the time of the encounter, I did not know that an erythema migrans lesion is considered pathognomic for Lyme disease. This symptom is considered so conclusively diagnostic for Lyme disease that it is stated as such by the National Institutes of Health (NIH) and Kaiser Foundation’s Lyme Disease Executive Summary. The NIH refers to the erythema migrans as **“the only distinctive hallmark unique to Lyme disease.”**

Dr. Spindel writes, **“Upon seeing a picture of erythema migrans, he recalled having a similar rash.”**

If it were not for the erythema migrans, which does not always occur, I would have not suspected Lyme disease. The lesion I had was a classic presentation of an erythema migrans rash. It is described in the written summary I had provided to Dr. Spindel. A classic erythema migrans cannot be confused with another rash. It was an expanding circular red **“bull’s-eye”** rash reaching almost ten inches in diameter, well beyond the five centimeter minimum specified by the NIH. It is the key clinical presentation of early-stage disseminated Lyme disease.

I described this rash to Dr. Spindel during the encounter as well as the subsequent satellite rashes I had. A photo of an erythema migrans similar to mine was provided in my written summary. He did not ask any questions with regard to this definitive symptom. Either Dr. Spindel does not understand the significance of this specific, elementary, and critical symptom or he purposely chose to ignore it.

Three different times during the encounter I asked Dr. Spindel what other diseases commenced with an expanding circular red “bulls-eye” rash (reaching a diameter of almost ten inches), followed by symptoms similar to mine involving cardiac, neurologic, ophthalmologic, and arthritic disorders. The first time I asked him to name these diseases, he replied there were “many, many, many”. The second time I asked him to name some of these diseases, he replied there were “many, many”. The third time I asked him to name even one disease, he replied there were “many.”

He was unable to give me even a single example of another disease that fits these criteria because there are none.

- 3) Dr. Spindel writes, He...voices concern about “conspiracists” among the physicians and investigators that have outlined guidelines for diagnosis and treatment.”

This is a fabrication and a blatant lie. During the encounter, when Dr. Spindel accused me of believing in conspiracies, I found his comment so bizarre and out of context, I made a written note of it. When I saw in my medical report that he had written I was voicing concern about “conspiracists”, I was astounded and infuriated. Dr. Spindel alluded that I believed in “conspiracists” during the encounter and then twisted this around to write that I was rambling about “conspiracists” in his written report. “Conspiracists” is not a word. The word that this clinician seeks is “conspirator.”

Dr. Spindel also writes, “He brings with him...a 27 page internet (sic) article authored by a Dr. Joseph J. Burrascano Jr. to support his position. The article contains many inaccuracies, mis-spellings (sic), anecdotal data and frankly outlandish statements regarding antibiotic properties and treatment.”

The inspiration for this clinician’s comment about “conspiracists” comes from testimony given by Dr. Burrascano at the invitation of the U.S. House of Representatives. The title of the speech was “The Lyme Conspiracy.” It is obvious that Dr. Spindel knew of this testimony since we did not discuss Dr. Burrascano or his speech during the encounter. In fact, at the time of the encounter, I do not believe I was even aware of Dr. Burrascano’s testimony.

After a prolonged absence (of ten minutes or more) from the room, Dr. Spindel returned and it was evident that his demeanor had markedly changed and he

became quite hostile and rude. He informed me that he and Kaiser Permanente adhered to the protocols of Dr. Allen Steere for the diagnosis and treatment of Lyme disease.

I learned later that Dr. Steere was also present in the session before the U.S. House of Representatives where Dr. Burrascano spoke of “The Lyme Conspiracy”. During this session, Dr. Steere was not well received. This could partially explain Dr. Spindel’s hostility towards me and his slander of Dr. Burrascano. His exact comment to me with regard to Dr. Burrascano’s monograph, “Some people write well.” This was stated with a sarcastic tone.

This hostility and bias is also evidenced by the following written comment by Dr. Spindel, “They believe that there is no way to exclude the diagnosis of Lyme in the presence of numerous non-specific symptoms.” “They also believe “their literature” that states that non-response to abx requires recurrent or longer courses of abx as well as higher dosages than standard recommendations.” “He verbalizes frustration with “the system” that does not agree with his diagnosis.”

They believe? Their literature? He verbalizes frustration with “the system”? None of the above was discussed during the encounter. It should be quite obvious from these comments that Dr. Spindel was hostile and biased.

With regard to his comment about “numerous non-specific symptoms,” an expanding circular red “bulls-eye” rash reaching almost ten inches in diameter is not a non-specific symptom. It is considered diagnostic by the NIH.

- 4) Dr. Spindel writes, “I spent most of the visit listening to all of his signs/symptoms and reasoning...”

This is also a lie. Less than ten minutes, at most, was spent mentioning place of exposure, a few symptoms, and “reasoning.” Other than the erythema migrans, dizziness, and cognitive function, my symptoms were not discussed. Dr. Spindel has simply listed what I had provided in written format, giving the impression that he was attentive during the encounter. He did not “listen” to any of this. We did not discuss any of the symptoms I had provided in written form. He did not ask any questions with regard to my symptoms.

Dr. Spindel writes, “he postulates his exposure to ticks would have been home near Battle Ground or...during trips to...California.” “He does not recall a tick bite.”

The probable place of exposure was the only diagnostic question Dr. Spindel asked of me. He agreed that California was a highly endemic area for Lyme disease and also said that Lyme disease was extremely rare in Oregon and Washington. (The Centers for Disease Control show the entire West Coast (California, Oregon and Washington) as endemic for Lyme disease).

**I did not say or write that I did not recall a tick bite. I said I did not see a tick. The tick bite is evidenced by the erythema migrans. According to the NIH, “Although a tick bite is an important clue for diagnosis, many patients cannot recall having been bitten by a tick. This is not surprising because the tick is tiny, and a tick bite is usually painless.”**

**Insofar as “reasoning,” I pointed out that my symptoms were indicative of central nervous system infection. That is all.**

**Several times during the encounter I asked Dr. Spindel what symptom or symptoms would be an indication of Lyme disease. Each time he would not or could not answer. His verbatim response was he “didn’t want to tell me”.**

- 5) Dr. Spindel writes, “I also advised him that I would research the topic some more and as new data comes (sic) available and let him know if I changed my opinion.”**

**Dr. Spindel never told me this or any comment that could be interpreted to have a similar meaning.**

**Well before the encounter, I provided Dr. Spindel a Chronology and Summary of Symptoms for him to read. He had not read these prior to the encounter. What Dr. Spindel did tell me was that he would read my Chronology and Summary of Symptoms and see if he “found something that would make him change his opinion.”**

**In essence, Dr. Spindel concludes I do not have Lyme disease without having read my prepared material, without discussing my symptoms during the encounter, and admitting in his own report that he “would have to research the topic some more.”**

**It is inconsistent that a clinician who writes that he would have to “research the topic some more” to be able to provide a diagnosis for Lyme disease knows enough to tell someone they do not have it.**

- 6) A number of times during the encounter I asked Dr. Spindel why he was convinced my symptoms could not possibly be due to Lyme disease. His reply was that I had “too many symptoms” for him to give a diagnosis of Lyme disease.**

**The NIH defines Lyme disease as “A systemic, tickborne disease with protean manifestations, including dermatologic, rheumatologic, neurologic, and cardiac abnormalities.” In addition, the NIH has thus far identified 55 species and 321 strains of the causative agent of Lyme disease, *B. burgdorferi* and the disease is still being investigated and defined. The Centers for Disease Control states,**

**“Evidence is accumulating that the different genospecies are associated with somewhat different disease expressions.”**

**According to the NIH, it is precisely a “constellation of symptoms” to which Dr. Spindel refers that defines Lyme disease. And those symptoms can vary from one case to another. This is at complete odds with Dr. Spindel’s opinion.**

**The listing of symptoms which I provided were primarily constructed from my medical records. I listed unusual symptoms that appeared after the erythema migrans. It is possible that some of these symptoms are not Lyme related. That should not have precluded symptoms that are associated with Lyme disease. Some of the symptoms listed that are clearly linked with with Lyme disease include erythema migrans, preventricular contractions and ventricular tachycardias, shoulder and wrist pain and weakness, neck pain and stiffness, knee pains, muscle soreness and fatigue, general fatigue, vision symptoms, cognitive disorders including difficulty concentrating and thinking, decreased short-term memory, and disorientation.**

**Dr. Spindel writes, “The patient does not suffer from or have a h/o any atrioventricular blocks, focal central or peripheral nervous system signs/symptoms, focal or migratory arthritis, objective ophthalmologic findings.”**

**With the exception of atrioventricular blocks, these symptoms have been documented as previously stated.**

**Dr. Spindel is not qualified to offer an ophthalmologic opinion. Shortly after this encounter, a follow-up visit with an ophthalmologist resulted in a diagnosis of 6<sup>th</sup> cranial nerve palsy. Cranial nerve involvement is a symptom of Lyme disease.**

**6)To summarize;**

- In May 1994, my dog, Bo, and I went on a trip to northern California, an area highly endemic for tick-borne diseases. It was the only extended trip I ever took with Bo.**
- On our return, I develop an unmistakable and classic erythema migrans distinctive to Lyme disease and, shortly thereafter, a cluster of satellite rashes in the same area as the large erythema migrans.**
- During the next six years, Bo and I develop progressively deteriorating multi-system health problems involving, but not limited to arthritic, neurologic, cardiac, and ophthalmologic symptoms consistent with late-stage disseminated Lyme disease as defined by the NIH and other sources. These are documented in my medical records and Bo’s medical records. No other member of my family developed these problems.**
- Dr. Spindel refused to provide any medical assistance despite repeated requests for help. This included failure to provide any differential diagnosis**

or any attempt to provide an alternative explanation for the symptoms which were consistent with the NIH definition of Lyme disease.

- **Dr. Spindel filed a false report with fabrications, omissions, and distortions of truth. Among other things, Dr. Spindel falsely states that I believe in “conspiracists,” even a word of his invention.**
- **In March 2001, I ordered and paid for a Western Blot IgG blood test, which is specific for Lyme disease. The results showed a banding pattern consistent with the highly restrictive NIH/CDC surveillance case definition for Lyme disease (see Kane rebuttal). In a recent clinical trial involving 11,000 patients, only one-fifth of those with culture-proven Lyme disease were able to show the presence of the number of bands which I showed. Dr. Spindel and his cohort deny the possibility of Lyme disease.**
- **Since the encounter, my medical record shows a finding of cranial nerve palsy, continued complaints of vision problems, an episode of extreme pain and swelling in my left hand and wrist (ER visit), continued problems with treatment resistant right shoulder pain and weakness where I had been given a steroid injection, and continued heart rhythm irregularities. All of these symptoms are consistent with Lyme disease. Dr. Spindel continues to deny the possibility of Lyme disease, continues to fail to provide any differential diagnosis or explanation, and continues to deny any medical assistance of any kind.**

**Patient Signature:**

**Miguel A. Perez-Lizano**

**Date:**

**Attachment:**

**Centers for Disease Control; Lyme Disease - Diagnosis**

**Cc:**

**David M. Lawrence, M.D.**