

July 17, 2002

Jerry M. Slepach, M.D.  
Kaiser Permanente Office East  
3550 N. Interstate Avenue  
Portland, OR 97227

Re: Lyme disease – denial of care by denial of diagnosis

Dear Dr. Slepach,

In December 2001, you were kind enough to respond to a request by Denise Honzel that you write to me about questions that I raised regarding failure to diagnose, and therefore treat, for Lyme disease. Your response had to do with a complaint I had filed against Steven Spindel, M.D. and a rebuttal against Dr. Joseph Kane, M.D., two clinicians under your responsibility. I have attached a copy of your response in the event you have forgotten about this matter.

I was overwhelmed by your letter and did not know how I should start a response to you. I am sure you will also appreciate that recovering from a serious bacterial illness that went undiagnosed and took away seven potentially productive years from my life has hampered my response time. After giving this much consideration I am enclosing, for the third time in association with this complaint, the Lyme disease diagnosis guidelines issued by the Centers for Disease Control. You may not have read these. I am also enclosing a monograph on Lyme disease issued by Sam Donta, M.D. If you have not heard of Dr. Donta, he is an infectious disease specialist at the Boston University School of Medicine. He is also a co-author of the treatment guidelines for early-stage Lyme disease issued by the Infectious Diseases Society of America. (Dr. Donta asked that his name be deleted as an author of the guidelines as his name was used without permission and he disagreed with the guidelines). Dr. Donta is regarded as an authority on Lyme disease. In addition, you will also find the Lyme disease section of the U.S. Senate Appropriations Bill passed earlier this year.

I will not bother with again providing copies of my complaint and rebuttal since I doubt that these were given anything more than a cursory examination. These should be in my medical record unless they have been deleted. The rest of this response I will address point-by-point.

- One of the questions I asked in my letter to Ms. Honzel was whether you or any of your clinicians had any demonstrated expertise in the diagnosis and treatment of late-stage Lyme disease. I note that this was not answered.
- With regard to your comment that my “cardiac symptoms do not conform to the standard recognized cardiac manifestations of Lyme Disease,” I recommend you read the attached CDC statement on diagnosis as well as Dr. Donta’s monograph. If you are so inclined, I suggest you also read findings by Kornelia Kesler, M.D. of Yale University regarding cardiac involvement of Lyme disease. All of these sources define tachycardias (including ventricular tachycardias), pre-ventricular contractions, chest pain not related to exertion, and palpitations as symptoms of late-stage Lyme disease. I had all of these and more. And I am surprised that in your extensive examination of my medical record you did not

note that after my heart attack in 1982 until after I was infected in May 1994, I had none of these symptoms. AV block, one of the cardiac symptoms associated with Lyme disease to which you likely refer as “standard,” has been found to be uncommon in late-stage Lyme disease.

- With regard to your comment that your “review fails to document inflammatory joint findings,” I do not understand how you could have overlooked my frequent complaints of right shoulder pain for which I was given steroid injections and numerous physical therapy treatments. In addition, in the “Chronology of Symptoms” I provided to Spindel, I complained of knee pain, jaw pain, and stiff neck. Any reputable source will confirm that these are classic symptoms of Lyme disease. I will presume that this document is not “missing” from my medical record but I am providing you a copy just in case.
- With regard to your comment that your “review fails to document...definite neurological deficits that could be attributed to Lyme disease,” I am not exactly clear on what you define as a neurological deficit. If you are referring to objective clinical findings, you must have noted in your detailed review of my medical record that I was diagnosed for sixth cranial nerve palsy and optic neuritis. You may be unaware that cranial nerve involvement and optic neuritis are classic symptoms of neurological Lyme disease. It is clearly stated in the CDC information I have provided. If by “neurological deficits” you are referring to other symptoms of neurological involvement, I again refer you to the “Chronology of Symptoms” I provided which shows my complaints of dizziness, short-term memory, disorientation, difficulty concentrating and thinking, vision problems, and “tingling” sensations in my head and neck. The CDC and others recognize these as symptoms of Lyme disease. If by neurological deficits you are referring to cognitive testing, I had requested that this be done but refused the testing when I read Spindel’s report. At that point I lost my trust in Kaiser.
- You report that the Western Blot IgG I had done while a member of Kaiser and ordered by a Kaiser physician “are not available” for your review. I do not understand why this is not in my medical record. I am enclosing a copy for your review. The CDC considers the presence of five bands definitive for Lyme disease. This is explained in the Kane rebuttal. Kane’s reply to this test result was, “In view of Steve Spindel’s consultation and repeated negative EIA testing, I do not believe that the equivocal result on the Western Blot test... increases the probability that he has active chronic Lyme disease in any organ system.” Kane has used the negative ELISA, an unreliable and non-specific test, to deny the results of a specific test. (See below). In addition, he gives an unqualified denial of diagnosis without ever having seen me or spoken to me, violating CDC guidelines. Incidentally, I was denied the Western Blot IgG by Kaiser and had to pay for my own test.
- You state that “the standard serological studies that would support a diagnosis of previous Lyme infection have been repeatedly negative.” You are presumably referring to the two ELISA tests which were ordered. These tests are completely worthless for the diagnosis of late-stage Lyme disease and of little value in the diagnosis of any stage of Lyme disease. I cannot understand your failure to comprehend this. Please see the peer-reviewed referrals in the Kane rebuttal and Dr. Donta’s monograph for an explanation. This is a screening test used by the CDC for surveillance purposes, not for diagnostic purposes. It is neither specific nor accurate or reliable, even if properly done by a competent laboratory using appropriate strains.

- You state that the “bullseye” lesion following potential exposure in Northern California... may have been a self-limiting episode of Lyme disease. If so, how would this explain the chronology of symptoms I reported which developed following the tick bite and continued to persist for years? And that these symptoms are regarded by authorities in Lyme disease research as symptomatic of Lyme disease? And that these symptoms started to resolve with antibiotic therapy? Perhaps you have confused a self-limiting erythema migrans to mean the disease was self-limiting?
- If you have indeed read my complaint, I am surprised you did not ask why I state that your clinician, Dr. Spindel, filed a false report. I will provide at least one reason. In Spindel’s medical report, he stated that I had provided him a monograph on Lyme disease by Dr. Joseph Burrascano. In the event you are truly uninformed, Dr. Burrascano is a clinician in New York who in 1993 testified before the U.S. House of Representatives with the title of speech, “The Lyme Conspiracy.” Spindel was no doubt aware of this speech. Spindel then used this platform and his imagination to comment on “conspiracists” (his non-word) and states that I told him I believed in a Lyme conspiracy. This fabricated conversation was designed to destroy my credibility and never took place. This, in turn, triggered his pompous tirade on “their literature,” “outlandish statements,” “they believe,” “patients such as this get their information from...non-reviewed, non-mainstream...sources,” etc., which were also designed to damage my credibility. Of course, filing a false report may not be a matter of any importance in your view.
- Incompetence also doesn’t seem to be a problem with regard to your clinicians. Even if they state so as in Spindel’s report, “I also advised him that I would research the topic some more...and let him know if I changed my opinion.” It seems that Spindel knows enough to deny a diagnosis but admits he does not have the knowledge to provide a diagnosis. By the way, Spindel never told me what he claims to have told me.
- In your letter you state...“Further available diagnostic studies are unlikely to shed additional light on this (Lyme) matter.” I am providing a copy of a recent Western Blot IgM that was done. In case you do not know this, the Western Blot IgM is considered a test for active infection. Please note that this test result surpassed even the highly restrictive CDC surveillance criteria and shows bands specific only to *B. burgdorferi*, the Lyme bacterium. Kaiser also denied me this test and discouraged testing for other tick-borne diseases, such as babesiosis.

In the Western Blot IgM summary, I have crossed out the name of the physician to avoid harassment issues. I understand that an infectious disease clinician at Kaiser Permanente Northwest reported a physician in Oregon for the “overdiagnosis and overtreatment” of Lyme disease in the mid-1990’s causing a great deal of misery for this doctor. He was forced to discontinue his help to Lyme disease patients. This incident caused great harm to Lyme disease victims in the Pacific Northwest and the specter of harassment continues to this day. However, recent state legislative investigations regarding Lyme disease have led to laws and directives to prevent this type of abuse and protect both physician and patient. More legislative action is forthcoming.

Also enclosed is an article by The Academy of General Dentistry addressing Lyme disease. You may want to distribute this article to Kaiser dentists, who may be better qualified to diagnose this disease. Please note that Lyme disease can cause multiple dental treatments including root

canals. I reported an unusual number of root canals which were done following the tick bite after having only one root canal procedure in 55 years. Spindel ridiculed this complaint along with other well-recognized symptoms of Lyme disease.

In closing, I plan to provide a copy of your letter, this response, and certain other documents to Phil Baker, head of the Lyme disease program at the NIH. In this way, he can clearly see an example of the type of behavior being addressed in the directives issued to the CDC by the U.S. Senate. And also to demonstrate that misinformed clinicians are a public health threat because of the risk of transmitting tick-borne diseases in blood transfusions. The American Red Cross has issued guidelines prohibiting donors with Lyme disease and babesiosis but depends on honest and competent clinicians for diagnosis.

I am also providing a copy of this documentation to Daniel Zingale of the California Department of Managed Health Care who I am informed is collecting information regarding Kaiser and Lyme disease.

Of course, I would be interested in knowing any additional reasons why you are convinced I have never had Lyme disease or do not now have Lyme disease.

Thank you for your comments.

Yours Truly,

Miguel A. Perez-Lizano  
18715 NE 132<sup>nd</sup> Avenue  
Battle Ground, WA 98604

Cc;

Denise Honzel  
Phillip Baker – NIH  
Daniel Zingale – California Department of Managed Health Care  
Other Interested Parties

Enc;

Letter from Jerry Slepach, M.D. – December 13, 2001  
Centers for Disease Control – Lyme Disease - Diagnosis  
Centers for Disease Control – Lyme Disease – The Bacterium  
Lyme Disease Monograph by Sam Donta, M.D., Boston University School of Medicine  
U.S. Senate Appropriations Bill – Lyme Disease  
Chronology of Symptoms – Perez-Lizano  
Western Blot IgG – Perez-Lizano  
Western Blot IgM – Perez-Lizano  
American Academy of General Dentistry – Lyme Disease