

Testimony of Marty Ross MD
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The House Health Committee
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I am Marty Ross MD a Lyme Literate Medical Doctor from Seattle, Washington. I have treated hundreds of people from Oregon for acute and chronic Lyme disease. I come before you today seeking your intervention for the thousands of people that have or will acquire Lyme in Oregon. Today these people suffer because they cannot find medical doctors in Oregon who will adequately treat them.

Lyme disease is a debilitating illness when it is not correctly treated with 30 days of antibiotics within 30 days of the initial tick bite. Left untreated it causes many symptoms including poor cognition, body and joint pains, nerve dysfunction and severe fatigue. The disability from chronic Lyme that is not correctly treated is worse than that of severe heart failure.

Unfortunately in my experience many with Lyme disease in Oregon are misdiagnosed and not treated for Lyme when early intervention makes the greatest difference. In addition those with chronic Lyme cannot get treatment from qualified physicians because the Oregon Medical Board looks negatively on medical doctors that treat Lyme disease for more than one month. There seems to be a prevailing and incorrect view perpetuated by The Oregon Health Authority and The Oregon Medical Board that Lyme disease does not exist in Oregon and that when present is easily treated with one month of antibiotics.

Lyme Exists In Oregon and Is Under-Reported

Lyme disease is caused by a bacteria called borrelia and other co infections that are spread by the bite of a tick. There are studies conducted by University California Davis showing up to 40% of ticks from northern California carry Lyme. By proximity, Oregon likely has such rates of tick infection with Lyme. Yet, it is my opinion the Oregon health authorities think borrelia knows borders and that Lyme does not exist in Oregon. Therefore they do not educate providers to consider Lyme disease.

There is another reason that reported and confirmed cases of Lyme are limited. Without clear guidance on when to suspect Lyme cases most doctors do not know to think of a Lyme diagnosis or to even test for it.

According to the US Centers for Disease Control and Prevention (CDC) Lyme is always a clinical diagnosis based on risk factors of getting a tick bite and symptoms. Yet most physicians will not diagnose Lyme unless there is a history of a known tick bite, a bulls eye rash, or positive testing. Yet studies show

- individuals with Lyme remember a tick bite only 50% of the time,

- the bulls-eye rash occurs fifty percent of the time, and
- the lab testing method recommended by the Oregon Health Authority, Infectious Disease Doctors, and the US Center for Disease Control and Prevention misses Lyme 50% of the time.

Because there is an opinion that ticks do not carry Lyme in Oregon and providers do not know when to look for Lyme or how to diagnose Lyme is largely under-reported in Oregon giving a false sense that it does not exist.

Acute Lyme Disease

Most with acute Lyme in Oregon are not diagnosed. Acute Lyme is an illness that occurs within 30 days of a tick bite. The CDC states Lyme is always a clinical diagnosis that should be considered **even without a known tick bite**. It should be considered based on symptoms and risk of exposure to ticks.

These symptoms include but are not limited to fever and chills, flu-like symptoms, fatigue, joint pains and swelling, neuropathy including numbness or nerve pain, headaches, and mental confusion. When a person has been doing outdoor activities or has a known tick bite, Lyme should be considered. When the possibility of Lyme is high, even when testing is negative at least 30 days of treatment should be given with antibiotics.

When a clear diagnosis of Lyme is made the CDC and the Infectious Disease Society of America allow for 30 days of treatment with antibiotics only. However, studies show that even when acute Lyme is treated for 30 days, up to 60% of people will have symptoms that persist. These people should be treated further to prevent long term problems and a condition known as chronic Lyme disease. However the prevailing standard based on the CDC and IDSA guidelines is that only 30 days of antibiotics should be given. Unfortunately this is the standard that has been followed by the Oregon Medical Board. Because of this many with acute Lyme in Oregon develop chronic Lyme disease.

Chronic Lyme Disease

Chronic Lyme disease occurs when acute Lyme is not treated adequately or if it is not treated at all. In chronic Lyme a person can have severe fatigue, muscle and joint pains, cognitive impairment, numbness, nerve pain, poor sleep, sweats, abnormal heart rhythms, shortness of breath, imbalance, and a host of other symptoms. Once Lyme becomes chronic it can take years of treatment to gain health.

Treating Chronic Lyme Is Complex and Takes Time

Unfortunately most doctors follow the treatment guidelines of the IDSA. These guidelines call for less than thirty days of treatment only. These guidelines are largely based on opinion and

not supported by science. They do not work for most people who remain ill and debilitated. These are the guidelines used by most physicians in Oregon. Following the IDSA guidelines Oregon medical doctors do not risk their medical licenses but patients continue to suffer.

The International Lyme and Associated Disease Society (ILADS) has published evidence based guidelines. These guidelines consider both the benefit and risk of treating or not. They call for ongoing short or long-term treatment based on clinical assessment of a treating physician.

In my experience using an approach similar to the ILADS guidelines with treatment 90% of people get improvement. An average treatment length is 2 years. Improvements can range up to 100% but most are left with some degree of impairment. These treatment guidelines work and help those with this illness. Again the 30 day only treatment approach called for in the IDSA guidelines leaves up to 60% of people with ongoing disability and health impairment.

About Oregonians with Lyme

I treat Lyme using the ILADS guidelines. Because I do, people from Oregon who have Lyme get help and can lead full and productive lives. In my opinion though they should not have to travel to get such care. I have a number of colleagues in California and Washington State who treat Oregonians because care is not available in state.

Furthermore, when I have patients from Oregon that require a local physician to write prescriptions or to coordinate care, I cannot find ones who will follow my care plans. For instance my patients with Kaiser Health are not able to find physicians to write for my recommended antibiotics. They have to pay out-of-pocket for these prescriptions.

Doctors in Oregon Lose Their Licenses for Treating Lyme

In the past, physicians who have treated Lyme disease for more than 30 days in Oregon have lost their medical licenses due to disciplinary action of The Medical Board. This hostile environment scares physicians into not treating acute and chronic Lyme disease. Because of this there are currently no medical doctors in Oregon who treat chronic Lyme disease. And most are not adequately prepared to diagnose or treat acute Lyme disease.

Recommendations

1. Physicians in Oregon should be able to treat Lyme disease as they see fit using the ILADS guidelines as a standard of care. Such physicians should be protected from adverse actions by The Health Authority and The Medical Board. With the ILADS approach up to 90% will have improvements ranging to 100%. The IDSA guidelines do not work and leave people disabled. A better standard of care is needed for Oregonians such as that offered by the ILADS guidelines.

2. As part of an effort to educate physicians about the new ILADS standard of care for treating Lyme in Oregon, The Health Authority should educate physicians that Lyme does exist in Oregon and is much more prevalent than previously thought. In addition in considering a diagnosis, clinical standards should be used. They should inform such physicians that a Lyme disease diagnosis does not require a positive test, history of a bull's-eye rash, or even a known tick bite. Rather as the CDC notes, a Lyme disease diagnosis can be made based on symptoms and consideration of the risk of getting a tick bite.

Note: Contact Marty Ross MD for references regarding studies noted in this testimony. Dr. Ross is available at 800 470-7217 or by email: docmarty@thehealingartpartnership.net