Dr. Stephen Heppe & Mary Jane Heppe
1011 Hutson Road; Hood River, OR 97031

March 25, 2015

Testimony In Support Of SB916

We are writing in support of Senate Bill 916, which directs the Oregon Medical Board and the Oregon State Board of Nursing to adopt new rules regarding the diagnosis and treatment of Lyme disease. ***Mary Jane and I urge you to support the bill as is, without any amendments that could erode its protection of medical professionals in our state.***

Lyme disease is an insidious illness, and our medical professionals need flexibility within the full range of established medical guidelines in order to diagnose and treat this disease according to their best medical judgment.

Our family has experienced this disease first-hand. One of us (Mary Jane), started showing symptoms in 1998. But she never saw a tick bite and never got a rash. Blood tests for Lyme disease remained negative for several years (we have since learned that the two-tier testing protocol frequently applied, here in Oregon as well as elsewhere, misses more than half the patients who actually have the disease).[1] Mary Jane went through multiple doctors and multiple false diagnoses, including fibromyalgia, chronic fatigue syndrome, multiple sclerosis, and mental illness, while her symptoms worsened. She also had two medical procedures based on doctors' recommendations, which in hindsight were unnecessary, before finally being correctly diagnosed in 2005. By that point, seven years after the onset of symptoms, she was severely disabled. From personal experience, we know that Lyme disease is difficult to diagnose and can be extremely debilitating.

Mary Jane has now essentially recovered, but it has taken literally years of very aggressive and expensive therapy. ***Tellingly, no medical doctor in Oregon has helped with this recovery.*** We have not found a single MD in Oregon who is willing to diagnose and treat this disease (and its co-infections) with the long-term therapy needed. Instead, at great expense, we rely on doctors in California.

---

[1] The blood tests used in Oregon (ELISA and Western Blot) are ***indirect***, and work by detecting antibodies circulating in the patient's blood rather than the Lyme disease organism itself (Borrelia burgdorferi, or Bb). If a patient is not generating a sufficient quantity of antibodies, due to e.g. a compromised immune system, the test will be negative. Furthermore, there are many strains of Bb and the reference strain used for routine diagnostic testing is not equally sensitive to all of them. Finally, poor laboratory procedure, such as holding blood samples for days or weeks in order to perform all Lyme tests in a "batch" (thereby reducing laboratory expenses), degrades the samples and reduces sensitivity further. The College of American Pathologists has concluded that the currently available ELISA assays for Lyme disease do not have adequate sensitivity to be part of the two-tiered approach of the CDC/ASHLD, whereby only ELISA-positive samples can be tested by Western blotting. Bakken, et. al., J. Clin. Microbiol. 1997 537-543. Yet this two-tiered approach is applied here in Oregon.

In our Lyme disease support group here in Hood River (population 7500), we have two dozen formal members. We are also aware of roughly 100 people in the area with Lyme disease (roughly 1% of the local population). Their stories are similar – years of misdiagnoses as symptoms worsen, and a complete inability to find a practicing MD in Oregon that will diagnose and treat the illness with the long-term therapy that is needed. These folks either rely on Naturopaths (who have greater freedom to practice according to their medical judgment, compared to our state's MDs), or attempt to self-treat.

Our house pets and horses can get Lyme disease here in Oregon and receive effective treatment, yet the human population cannot. This is a sad testament to the politicized nature of this disease.

As you know from other testimony, there are currently two "standards of care" for Lyme disease. One standard of care, promulgated by the Infectious Disease Society of America (IDSA), suggests that Lyme disease is hard to catch and easy to treat. This is the only standard of care currently recognized in Oregon. The second standard of care, promulgated by the International Lyme and Associated Diseases Society (ILADS), recognizes that Lyme disease is easily misdiagnosed, that the disease can progress to a chronic condition if not treated early, and that long-term therapy may be needed in the case of chronic disease. In selected forward-looking states across the United States, doctors can practice according to this standard of care without fear of improper reprisal. Yet, if an MD in Oregon attempts to treat according to this standard, he or she literally risks their professional livelihood due to improper disciplinary action exercised by the governing board. ***Doctors need the flexibility to practice according to either standard of care, in accordance with their best clinical judgment.***

Please help! This legislation will enhance options for patients who are seeking diagnosis and treatment for Lyme disease in Oregon. The bill that I am asking you to sign, Senate Bill 916, will allow practitioners to act in the best interest of the patient, within scientifically-recognized standards of care, without fear of punishment from the professional disciplinary system.

Thank you for your support.

Stephen B Heppe Mary Jane Heppe

Dr. Stephen Heppe (D.Sc.) and Mary Jane Heppe
Hood River, OR
541-953-6378
541-806-3114