Senate Health and Welfare Testimony - H.123– March 21, 2014
Harry Chen, Commissioner, Vermont Department of Health

Good Morning

We have all heard the personal stories of Vermonters who have suffered with Lyme disease, and I know the hopeless feelings having such an illness can bring.

Lyme disease is a serious infection caused by the bite of a tiny tick. When the snow melts, the ticks will soon be out again for the season. We can't get rid of the ticks.

What we can do is help people know how to prevent getting it—and help doctors know how to recognize and most effectively treat illness. If left untreated, Lyme disease can cause grave illness, affecting the skin, heart, nerves and joints.

Thankfully, Lyme disease is usually treatable with a few weeks of antibiotics without problems. We know that some people will have persistent debilitating symptoms even after treatment with antibiotics. But this does not mean they have an ongoing infection. The exact cause of this Post-treatment Lyme Disease Syndrome is unknown, but current evidence does not support it being a chronic infection. It may be an auto-immune response to the initial infection, something we see as a result of some other infectious diseases.

We also now know that people with Post-treatment Lyme Disease Syndrome respond to medications other than antibiotics. For example, in the case of chronic Lyme arthritis, the medication methotrexate (which is not an antibiotic) has proved an effective treatment. Most people with chronic symptoms related to adequately treated Lyme disease will improve within six months to a year. However, there is no evidence that taking antibiotics for a long time (months to years) helps and evidence that it could actually harm a person.

Allow me some observations.

Lyme is a reportable disease in Vermont. There is no question that its incidence is increasing. In 2006 we first saw a marked increase and this was the first year more reported cases were acquired in Vermont. In the past few years, we have seen 500 to 600 cases reported in the state, reaching an all-time high last year, with nearly 700 reports of people who were likely exposed in the state. Even this number almost certainly underestimates the actual number – as many cases of early Lyme disease require no testing and may not be reported. When I first started practicing in Vermont some 24 years ago, there were only a handful of cases of Lyme disease in Vermont, and virtually all of those people were exposed out of state.

H.123 allows physicians to follows guidelines set forth by the CDC, the Infectious Disease Society of America (IDSA) and the International Lyme and Associated Disease Society. The CDC, the Infectious Disease Society of America (IDSA) guidelines, the NIH, and virtually every evidence-based clinical decision-making resource support antibiotics for 10 days to 4 weeks. This is also consistent with guidelines in Canada and Europe. I am not here to debate the science, but I believe that the ISDA guidelines are evidence- based and valid. They have undergone intense scrutiny and review and, based on the framework in the handout, meet the standard of the weight of the evidence. That said, they are clearly not the last chapter in this story. In contrast, the International Lyme and Associated Disease

Society (ILADS) guidelines recommend longer courses of antibiotics – of weeks to months – and even longer courses for chronic symptoms. At the core of this disagreement is the question of whether the chronic symptoms are related to a continued infection.

There are still many unanswered questions and evidence is emerging all the time. One example is a recent study that used DNA testing to clarify that recurrent symptoms were reinfections with different organisms, rather than relapses related to earlier infections. In this circumstance, both sets of guidelines would recommend additional antibiotic treatment. I expect that, given the intense interest in chronic symptoms related to Lyme disease, at some point in the future we will have a better understanding of its cause and a window into potential treatments including a vaccine which is in development. I think we all agree that we need continued research.

Finally, I want to turn to the issue of guidelines and standard of care. Guidelines contribute to, but do not define, the standard of care. Competing guidelines such as is the case with Lyme disease further challenge any bright line definition of that standard. The standard of care is not a rigid or fixed line in the sand. It is not static, but constantly changing based on emerging evidence. Guidelines do not replace clinical judgment, and all clinical decisions are made in the context of each individual patient and his or her particular situation.

As Commissioner and a physician, I urge you to be cautious as this bill proceeds. It does not determine a standard of care, but it is only one away step from it. The bill stakes out a middle ground – it still allows Medical Practice Board to investigate complaints against caregivers, and to pursue allegations of harm, but it gives comfort to doctors and patients that prescribers will not lose their licenses simply for prescribing long-term antibiotics for the treatment of Lyme.

For the physician or other provider, these are complicated decisions that are and should be made taking into consideration the available evidence and the individual needs of your patient. All of these must be made in the context of the doctor-patient relationship. There is no current prohibition on long-term antibiotics for Lyme disease and it is worth noting, that the Board has not pursued any physician or physician's assistant for such a prescription.

Regardless of the outcome of this bill, we can make progress in combating Lyme Disease by educating Vermonters on how to prevent and recognize the disease.

- Be Tick Smart booklet, flyers, posters and tic ID cards
- Keep our website content up to date – including the "crowd sourced" Tick Tracker mapping application launched in September 2013
- News releases and media interviews
- Community presentations
- Learning modules for elementary schools
- Video PSA contest for high school students

We can educate Vermont providers to ensure appropriate diagnosis and treatment.

- Up to date website content
- Infectious Disease Bulletin
- Health Alert Network (e-alert system)
- CME conferences for providers in 2012, 2013 and upcoming in 2014
- Focus at our Infectious Disease Conference in October 2013

We can keep ourselves informed about the issue.

- Continual evaluation of the medical literature
- Population based tick testing with Lyndon State and AAG
- Continue to meet with Lyme disease advocates
- We are also working with a Lyndon State College researcher on a tick and tickborne pathogen tracking project. Ticks are being collected from 12 sites around the state, and tested to determine if they carry Lyme disease and two other tickborne diseases.

In summary, I do not support the bill before you as based on sound public policy. Intervening in a scientific controversy is a worrisome precedent. Despite this I would acknowledge that the bill before you is considerably better than as introduced. I understand legislators desire to act on behalf of their constituents. If passed, H.123 as passed by the House is a middle ground proposal I can accept. It is important that move forward to meet the challenge of the increasing incidence of Lyme disease in Vermont, and plan to address it based on the best scientific evidence available today, while keeping an open mind to whatever new information tomorrow may bring.