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ORAL TESTIMONY TO THE TO THE SENATE TASK FORCE ON LYME AND TICK BORNE AND
THE SENATE STANDING COMMITTEE ON HEALTH August 29, 2017

I would like to thank Senator Serino, Senator Hannon, and members of the Task Force on Lyme and TBDs and Health committee for inviting me to speak to the committee.

- ★ Through my experience as the Membership Chairman of ILADS and as a practicing physician in Rhinebeck and Albany, New York, with an almost 30 year expertise in diagnosis and treatment of Tick Borne disease, I am struck by the compelling stories told by both patients and physicians, about the difficulties dealing with the many facets of Tick Borne disease.

- ★ Adhering to older and outdated guidelines for Tick Borne Disease are hampering physicians from taking care of patients.

ILADS Mission Statement :

1. Improve Physician understanding of Lyme Disease
2. Review, develop, and implement research programs and embrace the management of Lyme and associated diseases.
3. Advance the standards of care for Lyme and its associated diseases.
4. Review, develop, and implement programs for physicians and other health care providers support (ie: materials, advice, education)

ILADS Guidelines:

- ILADS has developed guidelines in accordance IOM guidelines
This document provides a detailed review of the medical literature and guidelines not based on low quality, opinion based evidence. We have a patient approach and that recommends a physician perform an individual assessment of the risks / benefits and various treatment options with appropriate follow up, allowing time to adjust therapy as new circumstances evolve.

- ★ New Guidelines are available on the National Guideline Clearinghouse web site

- ★ It is imperative that we educate physicians on the concepts of Tick Borne Disease. New concepts on the diagnosis and treatment of these diseases will give them a wider perspective in dealing with complicated Lyme symptoms.
- ★ ILADS offers a fundamental course for Physicians that is given on the day prior to the annual conference.

Diagnosis of Lyme Disease

ILADS Guidelines 2B

- ★ Lyme Disease is a great pretender.
- ★ Lyme Disease is a clinical diagnosis supported by laboratory testing. This is stated on the CDC website
- ★ Negative Lyme ELISA (Screening lab test) does NOT rule out Lyme Disease.
- ★ I see patients that present to my office with Tick Borne Disease symptoms, who have a negative ELISA screening test, and have been told they do not have Lyme Disease. These patients are usually sent to see many specialists. They receive many tests such as MRIs and CAT scans, many times, the tests come back negative and then after being treated for Lyme, in many cases, their symptoms are resolved or improved.
- ★ Each patient is a case history of one.
- ★ Absent of proof, is NOT prove of absent.
- ★ ELISA testing is only 49% sensitive.
- ★ Use of Western Blot Reflex test is inadequate. A negative “two tier test” does not rule out a diagnosis
- ★ We are seeing an increase in numbers of different co-infections:
 - Bartonella
 - Babesia
 - Rocky Mountain Spotted Fever
 - Relapsing fever (borellia Hermsii)
 - Anaplasmosis
 - Ehrlichia
 - Q Fever
 - Viruses, ie : Powassen

Lab testing in NYS:

1. Tick pathogen testing should be done in NYS. Presently, analysis has to be sent to IGENEX, in California, or Tick Spot in Massachusetts.
2. There are certain Tick Borne Disease labs that can be performed in all others states, EXCEPT NYS. This is hampering physicians in their task to help patients. A few examples are listed below
 - MDL labs
 - GALAXY labs
 - MILFORD MOLECULAR DIAGNOSTICS
3. It is paradoxical that we know that there are new strains of Tick Borne illness causing disease in people in NYS. i.e. Miyamotoi and Mayonii (rare).. There is excellent testing available, but NYS does NOT allow physicians to perform these tests on NYS patients.

Tick Transmission

ILADS Guidelines 1B

- ★ The Guidelines for Tick Borne transmission according to the CDC is 24-36 hrs. In my experience and according to some studies, it is possible to transmit disease after being attached , in some cases for only 6-12 hrs
- ★ New guidelines for tick bite prophylaxis dispute the notion that a patient can take 2 capsules of Doxycycline to prevent subsequent infections.
- ★ It is important to know how best to detect and treat Lyme disease and coinfections, to prevent future chronic illness, because the longer any infection has been present in a patient ,the more difficult it may be to subsequently treat.
- ★ Research on other possible modes of vector transmission, i.e. mosquitos, sexual

Treatment of Tick Borne Disease

ILADS Guidelines 2 D

- ★ Treat clinically

★ Awareness and treatments of co-infections

★ Patient centered care

★ Research on Persistence of infection vs. PLDTS

★ Out of the Box Quick illustrative cases

I feel that expanding current guidelines and improving preventive measures, diagnostic and treatment protocols will allow physicians to improve treatments for Tick Borne Diseases. Hopefully, these changes will make a positive impact on this epidemic.