Lyme Disease Prevention Task Force

Report

June 1, 2015

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Lyme Disease Prevention Task Force Members

- *Co-Chair* Sen. Ernesto Lopez, Senator for the 6th District
- *Co-Chair* Speaker Pete Schwartzkopf, Representative for the 14th District
- Sen. Bruce Ennis, Senator for the 14th District
- House Minority Leader Daniel Short, Representative for the 39th District
- Danielle Blount, Office of Governor Jack Markell
- Linda Parkowski, Delaware Economic and Development Office
- Dr. Awele N. Maduka-Ezeh, Department of Health and Social Services
- Dr. Heather Hirst, Department of Agriculture
- Dr. William Meredith, Department of Natural Resources and Environmental Control
- Linda Wolfe, Department of Education
- Sandra Reyes, Public member appointed by the Governor
- Judy Setting, Public member appointed by the President Pro Tempore
- Dr. Kathy Spreen, Public member appointed by the Speaker of the House
- Marlena Gibson, Delaware Housing Authority
- Pamela Sidman, Delaware Healthcare Association
- Dr. Steven Eppes, Medical Society of Delaware
- Bonnie Hudson, Delaware State Education Association
- Karen Panunto, Delaware Nurses Association
- Dr. Kathryn Wotman, Delaware Veterinary Medical Association

Auxiliary Members

- Paula Eggers, Infectious Disease Epidemiologist, Division of Public Health, Department of Health and Social Services
- Marilyn Williams, Lyme Disease Association of the Eastern Shore

Support Staff

- Lauren Cutajar-Wynne, House of Representatives

Public Participants

- Many thanks to the many members of the public who regularly participated in the task force meetings. Special thanks to Beverly Sisson, Rebecca Benson, Pamela Andrews, Elise Kenton, Lisa Ray Kenton, Chuck and Diane Mulholland, Brian Bennett, Alina Pfeifer, Frank Szczuka, Dean Simpson, Desmond Kahn and Dr. Henry Childers.

Preface

In 2013, Delaware had the sixth-highest incidence of Lyme disease in the United States; the northeast region alone reported more than 94 percent of confirmed Lyme disease cases across the country that year. State health agencies document approximately 30,000 cases of Lyme disease annually, but it is well known that the actual incidence is as much as 10 times greater due to the high volume of unreported cases. The Centers for Disease Control has clarified that the number of people diagnosed with Lyme disease each year in the United States is around 300,000. Delaware, along with our neighboring states, are in the red zone for Lyme disease. According to the Centers for Disease Control, 96% of reported cases occur in 13 states clustered in the Northeast and upper Midwest. This means Delaware has a greater need to understand and respond to Lyme disease than other states.

Lyme disease is caused by the bacterium *Borrelia burgdorferi* and is transmitted through the bite of an infected tick. Typical symptoms include fatigue, fever and headache. Newly diagnosed patients generally are treated with a course of antibiotics. Without treatment, the infection can damage the joints, heart and central nervous system, resulting in meningitis, temporary facial paralysis and impaired muscle function. Even with treatment, a number of patients will experience chronic symptoms.

Because prompt diagnosis and treatment help to preclude the most severe Lyme disease symptoms, state and federal agencies must prioritize prevention education while supporting research for better diagnosis and treatment options.

The Delaware Lyme Disease Task Force was initiated after a number of constituents had difficulty with the diagnosis and treatment of their Lyme and other tick-borne diseases. Lyme disease patients often report that they experienced misdiagnosis, bouncing from doctor-to-doctor, and denial of insurance coverage when seeking treatment. Prominent figures in Delaware have been diagnosed with Lyme disease including WNBA star Elena Delle Donne and Miss Delaware 2013 Rebecca Jackson. The goal of the Lyme Disease Prevention Task Force is to make recommendations regarding the need for a unified strategy to combat Lyme disease and other tick-related diseases in Delaware.

Controversies around Lyme Disease:

Along with limited health care provider knowledge regarding these illnesses, a major factor that complicates the management of Lyme is the considerable controversy around this condition.

Currently there are varying schools of thought that are often in direct opposition. In each case, many peer-reviewed articles can be cited in support of both sides of these issues. The major controversies include:

Does chronic Lyme disease exist?

> There is disagreement over whether a persistent form of Lyme disease exists. Although most patients with early Lyme disease who are treated with appropriate antibiotics recover uneventfully, some will have continuing problems, such as fatigue and neurocognitive symptoms. Patients with delayed diagnosis and treatment may have even

more severe clinical courses. The Infectious Diseases Society of America (IDSA) and the Centers for Disease Control (CDC) have applied the term "Post Lyme Disease Syndrome" in such cases, describing a scenario in which patients have persistent symptoms even after clearance of the causative pathogens. A different school of thought holds that there is much evidence that can be used to support the existence of persistent pathogens such as positive blood cultures, Herxheimer reactions when appropriate antibiotics are given, and the recurrence of symptoms in some patients when antibiotics are prematurely discontinued. The patients who attended the public sessions of the task force described their years-long struggles with the chronic form of the disease and the suffering of such individuals is important to keep in mind when considering whether chronic Lyme disease is real.

What is the best way to diagnose Lyme disease?

The erythema migrans rash, if present, is diagnostic of Lyme disease. However, many people never exhibit this characteristic finding. Current serologic (antibody tests) can be used to confirm the diagnosis in the majority of patients, but very early infection may not be detected and early antibiotic treatment can prevent the development of a serologic response. The CDC recommends two-tiered antibody testing. Only if an ELISA test is positive can the sample be tested for the more specific Western blot test. However, there is a prevailing belief that these tests miss at least half the positive cases. Public comments to the task force identified numerous false negative results on these tests. Traditionally, many insurance companies will not pay for treatment unless both tests were positive. The health care provider should consider the patient's history, physical examination, and review of systems to make the diagnosis. Many members of the task force believe that sources of information such as the CDC website have confusing and contradictory information. They hold that positive testing, especially sensitive tests like blood cultures, can be used in support of a Lyme diagnosis. A Lyme diagnosis should be based on clinical judgment, the diagnosis made by a licensed practitioner should be sufficient, irrespective of the results of the lab tests.

How is Lyme disease best managed?

The areas of controversy around the treatment of Lyme are many. Issues open to debate include length of treatment, single versus combination antibiotics, continuous regimens versus pulsed, and consideration of oral versus IV or IM administration.

Controversies around adequate preventive approaches and treatment for pregnant women abound. Concern has been expressed that children born with gestational Lyme can be debilitated by the disease and prevention is the key in turning the tide of this epidemic.

Probably the most contentious issue is length of treatment. Traditionally, the Infectious Diseases Society of America recommended treatment courses of 14-28 days, depending on the patient's clinical manifestations. On the other hand, the International Lyme and Associated Diseases Society has a more open-ended approach, essentially recommending treatment until the symptoms resolve. The public comments at the task force meetings underscore the sequelae that might result when treatment is inadequate. A possible resolution to these treatment arguments is to target the individual patient and to avoid cookie-cutter, one-size-fits-all regimens. Health care providers need permission to consider various options in the best interests of each patient and clarity that treatment guidelines are guidelines, not unbendable standards. In other words, providers should be enabled to use their best clinical judgment in caring for their patients, tailoring care on a case-by-case basis.

A number of other therapeutic modalities might also be considered. While appropriate antibiotics for a sufficient time have been the foundation of treatment, success has also been documented with herbals, supplements, nutritional support, and any number of ancillary treatments from psychotherapy to chiropractic. This is a vulnerable population and the task force does not condone the treatment advocated by those intending to defraud or exploit Lyme patients.

Agreement does not have to be reached between the opposing sides in order to move forward. Simply recognizing that disagreements exist should allow both sides to work around them in developing a balanced program. This ensures that health care providers can consider various options as they manage these often complex and debilitating cases. While there is intense controversy around Lyme disease, it does not need to impede progress.

Recommendations

The committee made a number of recommendations to improve Lyme disease prevention, awareness, treatment and coverage.

Recommendation 1: A robust public awareness campaign. The need for a public campaign on Lyme disease prevention and awareness is critical. This is a condition that potentially impacts every Delawarean, unlike most conditions that impact defined cohorts of people –by age, geographic residency, or underlying health conditions. Lyme disease can be prevented, but it requires every person to take personal responsibility for prevention and early identification.

Implementation:

- Target the following audiences: general public, children/schools (all levels), outdoor workers (subgroup: farmers/agriculture workers), outdoor enthusiasts (subgroup: hunters), health care providers.
- Use a message of prevention and Lyme disease awareness to encourage early detection and treatment.
- Secure a comprehensive Lyme disease public awareness campaign, media to include but not limited to: print, digital, radio, billboards, cinema, television and social media advertising. (Keep this broad and flexible as the technology changes, realizing how different audiences will receive the messaging.)
- Expand outreach to disseminate information through agencies and professional associations and to establish a more significant presence at community events throughout the state.

- Sources of sufficient funding for a statewide public awareness campaign need to be identified. One possible source to explore is the Delaware Health Fund (www.dhss.delaware.gov/dhss/healthfund/about.html). One of the primary purposes of the fund is to "promote preventive care for Delawareans in order to detect and avoid adverse health conditions." Clearly, Lyme disease prevention meets these criteria.

Recommendation 2: Improved health care provider understanding of Lyme disease. Educate all health care professionals to develop a high index of suspicion for Lyme disease since we are in an endemic area. Education should be done in a way that provides diagnosis and treatment options in a balanced way.

Implementation:

- Establish an oversight board to implement medical professional education on Lyme disease and to determine the content of medical education materials ensuring quality and balanced medical education. The board should have representation from the board of medicine, board of nursing, patient advocates and Task Force members.
- Educate all health care professionals that Lyme disease can be diagnosed clinically, based on history and physical examination. The test can confirm, but is not necessary to make, a clinical diagnosis.
- Encourage continuing medical education (CME) credits and nursing continuing education units (CMU) on Lyme disease and make this topic enticing to get medical providers to take courses now.
- Host CME/CMU trainings in all three counties. Try to host conferences in hospitals to get the most medical professionals together at once.
- Layer messages and deliver in different ways using professional associations, medical journals, radio and conferences as well as linking medical training with the public awareness campaign. Try to bring all health care providers together for collaboration.

Recommendation 3: Create a mechanism to connect patients to competent providers.

Recommendation 4: Promote appropriate insurance coverage for the care of patients with Lyme disease to ensure that insurance companies cannot refuse to pay for treatment if a licensed health care professional has clinically diagnosed a patient with Lyme disease.

Implementation:

- Engage with insurance companies and work collaboratively to improve coverage for Lyme disease patients.

Recommendation 5: Establish protection for health care professionals who treat Lyme disease patients. Ensure that physicians can treat individual patients using their best judgment and clinical diagnosis without fear of repercussions. This recommendation would not prohibit the Division of Professional Regulation from investigating egregious deviations from reasonable care.

Recommendation 6: Develop on a statewide basis a science-based Integrated Pest Management strategy incorporating acaricide use, biological controls, management of tick-host animals and backyard habitat management.

Implementation:

- Change state law to allow DNREC Mosquito Control to address ticks. For this agency to be involved in field control operations for ticks, there is a need to modify Mosquito Control's enabling statute to accommodate tick activities in Title 16, Chapter 19.

- Update and implement DNREC/DHSS proposal- "Development and Implementation of a Tick-borne disease prevention/abatement program" by creating two positions dedicated to tick-related work and operational support funding. Revisit the proposed positions to ensure the functions and placements of the positions align with the findings of the Task Force. Projected annual funds needed by DNREC for its portion of the program are $106,500 per year and similarly annual costs for DHSS's portion of the program are $61,100 per year.[1]

- Encourage and solicit additional research on tick biology and ecology with a Delaware-specific focus in order to determine evidence-based solutions in disease reduction methods.

- Consider a wide range of options for tick abatement in the Integrated Pest Management strategy including a reservoir targeted vaccine aimed at breaking the transmission cycle of the bacterium with small mammals.

Recommendation 7: Add Lyme disease to the Department of Defense's Congressionally Directed Medical Research Programs to allow for adequate research funding.

Implementation:

- Letter to congressional delegation soliciting their help to get Lyme disease added to the list.

<u>Conclusion</u>

Significant work is essential to raise public awareness, improve medical professional understanding, develop better diagnosis and treatment, and mitigate the impact of ticks in Delaware. This serious public health issue requires a continued dedicated response to implement the recommendations of this Task Force.

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[1] Appendix 9

Appendices

Appendix 1: Senate Joint Resolution 10

Appendix 2: Meeting Minutes, January 6, 2015

Appendix 3: Meeting Minutes, February 3, 2015

Appendix 4: Meeting Minutes, March 23, 2015

Appendix 5: Meeting Minutes, May 4, 2015

Appendix 6: Public Education and Awareness Subcommittee Meeting Minutes, April 13, 2015

Appendix 7: Medical Professional Education Subcommittee Meeting Minutes, April 20, 2015

Appendix 8: Subcommittee Reports

Appendix 9: DNREC/DHSS proposal- “Development and Implementation of a Tick-borne disease prevention/abatement program”