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Speaker of the House
STATE REPRESENTATIVE
14th District

DELAWARE GENERAL ASSEMBLY
STATE OF DELAWARE
LEGISLATIVE HALL
DOVER, DELAWARE 19901

Lyme Disease Prevention Task Force

Meeting Minutes- Tuesday, January 6, 2015

The Lyme Disease Prevention Task Force was called to order at 6:20pm by Sen. Lopez. Members present included co-chairs Sen. Lopez and Speaker Schwartzkopf, Sen. Ennis, Rep. D. Short, William Meredith, Linda Parkowski, Sandra Reyes, Judy Setting, Bonnie Hudson and Karen Panunto. Members participating via conference call included Danielle Blount, Dr. Heather Hirst, Linda Wolfe and Dr. Kathryn Wotman.

Marlena Gibson, Pamela Sidman Sen. Lopez and Speaker Schwartzkopf thanked the members of the Task Force for their participation and emphasized the seriousness of this issue to Delaware. Sen. Lopez highlighted the significance of numbers of co-sponsors the authorizing legislation, Senate Joint Resolution (SJR) 10, had in the 147th General Assembly.

The members introduced themselves sharing the constituency they represent as well as any personal interaction they had with Lyme Disease.

The committee reviewed the provisions of SJR 10 including the reporting deadline of June 16, 2015. The committee reviewed additional materials including a pamphlet on the basics of Lyme Disease and a presentation prepared by Dr. Kathy Spreen which provided a baseline of the scientific and medical information.

Speaker Schwartzkopf drew the committee's attention to the third slide in Dr. Spreen's presentation regarding her son's case of Lyme Disease which described misdiagnosis, bouncing from doctor-to-doctor and Lyme Disease denial. The Speaker emphasized the importance of making the process better for patients who have yet to be diagnosed. There are disagreements in the medical field over Lyme Disease and its treatment. The goal is to try to find some standards to guide medical professionals.

The co-chairs then opened the meeting to member discussion. Judy Setting shared her experience with a severe case of Lyme Disease. She emphasized the large population of people who are suffering and the disparity of treatment received by patients. She stressed the importance of doctors treating patients with Lyme Disease for the long-term.

Dr. Epes discussed the controversy among doctors who are willing to treat and test and others who are not. He identified prompt proper diagnosis as the key to improving patient treatment. Lyme Disease testing has become increasingly more reliable, but it is still not perfect. He stressed the importance of balancing medical research with the anecdotal testimony the committee considers.

Speaker Schwartzkopf inquired about the testing options doctors have at their disposal and asked if cost was a consideration for doctors. Dr. Eppes felt that cost was not an issue but that providers have not been familiar enough with Lyme Disease. The importance of education for doctors and physicians assistants cannot be understated.

Rep. D. Short provided perspective as a former employee of a health insurance company. The insurance company would only approve tests in Delaware and wouldn't allow patients to use a test from another lab. Delaware does not have any Lyme Disease specialty labs and many patients want to use labs in Maryland.

Dr. Eppes explained that there are problems with insurance coverage for prolonged treatment. Rep. D. Short clarified that private employers can cover the cost of a patient going to a lab out of network, but that it is probable that companies would only approve tests from labs in network.

Sandra Reyes shared her experience with Lyme Disease. She was able to get diagnosed once on her husband's better insurance plan; this required a spinal tap. She stressed the stigma that people think that Lyme Disease is like a flu and not a serious prolonged illness.

Linda Wolfe asked if doctors are able to determine what test a patient should have and which lab to be sent to. She wanted to know if doctors have a rubric. Dr. Eppes explained that people who have Lyme Disease and test negative are often in the first few weeks of the disease. After that time, the body will start to test positive. Negative tests when a patient is actually positive are not common after the first few weeks of the disease manifestation. Most negative results do not require treatment for Lyme Disease on a prolonged basis.

The standard labs used in Delaware are LabCorp, MedAssist and Quest. There are specialized labs that use alternative technologies out-of-state. Some of those labs are using new technologies that have not been approved by the Federal Drug Administration. There are no Lyme Disease specialty labs in Delaware. There is one in New Jersey and the most famous is in California. Most Lyme Disease patients are paying out-of-pocket for these expensive tests. There are also no Lyme Disease specialty doctors in Delaware, though there are some in Pennsylvania and Maryland.

Linda Parkowski requested that insurance companies join the conversation. She also suggested that the committee try to recruit a Lyme Disease specialist to Delaware. Speaker Schwartzkopf felt that recruiting a specialist to Delaware could be a recommendation of the committee and could be tied in with an economic development program.

Bonnie Hudson shared that when she worked in Pennsylvania they regularly were diagnosing Lyme Disease or other tick-borne diseases. As a school nurse in Delaware, she sees strange looking rashes and will refer the kids to their family doctors. But the family doctors haven't seen Lyme Disease enough and often think the kids have ringworm. She suggests more education along with a prevention strategy.

Dr. Wotman shared the practices for treating animals with Lyme Disease, predominately dogs. Veterinarians are comfortable recognizing the clinical signs of Lyme Disease and are fully aware

of the prevalence of Lyme Disease in our region. Veterinarians trust the test and are very comfortable diagnosing animals.

Linda Parkowski asked why dogs have a vaccine but humans do not. Rep. D. Short and Dr. Eppes gave the history of the human vaccine. The vaccine was developed by a pharmaceutical company, but it had adverse side effects including arthritis. The company faced a class action lawsuit and pulled the product from the market. The vaccine had an 85% efficacy, but many people thought that they were fully protected. Rep. D. Short suggested a competitive grant to have Delaware come up with a better test making Delaware a leader on Lyme Disease.

Bill Meredith shared the major concerns the Department of Natural Resources and Environmental Control (DNREC) has for Lyme Disease. Many staff people especially those who work in mosquito control regularly enter high-risk inhospitable areas. Lyme disease is an occupational hazard for many of the employees. Back in 2007, DNREC worked with the Department of Public Health (DPH) to develop a proposal to address Lyme Disease in Delaware. This proposal included adding a DNREC staff person who would serve as a researcher tracking and identifying hotspots and applying control measures. DPH would employ a trainer/educator to administer educational programs to the public and to the medical community. This proposal is shovel ready, but it never got off the ground due to funding problems. Sen. Ennis suggested leveraging federal grant money to pay for the proposal and not just relying on the state budget to get funding. Bill Meredith said he would look into funding from the Center for Disease Control.

Speaker Schwartzkopf brought the committee's attention back to Dr. Spreen's presentation. The map of cases of Lyme Disease in the country shows that Delaware and our region as the epicenter. The image really depicts how significant the problem is. Bill Meredith explained that the deer population, terrain and climate contribute to this problem. The committee requested the case numbers for Lyme Disease in Delaware as well as other tick-related diseases at the next meeting.

Judy Setting reiterated that most ticks are carrying many diseases and not just Lyme Disease. She pointed out that there are people who can have multiple negative tests for Lyme Disease before having a positive test, and she was one of them. If she didn't get the treatments for Lyme Disease when she did, she would have died.

Linda Parkowski suggested linking up with National Lyme Disease groups. Speaker Schwartzkopf highlighted the need for better testing for early detection and the importance of working with insurance companies to use the best labs. We have a number of high-profile people in Delaware who have Lyme Disease, including Elena Della Donne.

Sen. Lopez asked the committee members who have had Lyme Disease to identify one or two things they experienced that should never happen again. He suggested the committee attack the 'low-hanging fruit'.

Linda Parkowski said getting a family doctor to prescribe the antibiotics right away is essential to mitigate the impact of Lyme Disease. Sen. Ennis suggested establishing standards of need-to-know information based on models of care seen for trauma patients.

Dr. Eppes explained that Lyme Disease cases are notoriously underreported. Speaker Schwartzkopf asked if regional doctors realized the prevalence of cases compared to the rest of the country. Dr. Eppes felt that there was not widespread understanding of how common the disease was among medical professionals. He reinforced the need for education among healthcare providers.

Speaker Schwartzkopf reminded the committee that Delaware is in a crisis zone. He suggested that medical professionals see the map to help them accept that this as a serious and valid disease. The Center for Disease control estimates 300,000 cases of Lyme Disease in our region. Bill Meredith pointed out that the problem is not just the prevalence of ticks but how infected the ticks are. A Wesley College study in 1999-2000 showed that ticks carried Lyme disease at county-averaged rates of 62% for New Castle, 14% for Kent, and 40% for Sussex.

Linda Wolfe asked about prevention measures in Delaware. Pamela Sidman shared that Delaware does do a good job posting warning signs in tick infested areas to remind people to spray and check themselves. Public awareness about checking for ticks is visible, but there is a lack of public understanding when people get Lyme Disease.

Rep. D. Short recommended adding Lyme Disease treatment to the list of 39 mandated coverage requirements for health insurance.

Sen. Lopez opened the floor to public comment. Beverly Sisson shared her experience traveling from doctor to doctor with her Lyme Disease. She is now seeing a specialist in Maryland. She felt that each doctor was bouncing her to the next to treat individual symptoms of Lyme Disease while not addressing the underlying cause. She felt that the medical professionals had a bias on this issue and that if you do not have a positive test that you are going to struggle to get treatment. Lyme Disease can impact every organ in the body. She had two false negative tests and was finally clinically diagnosed.

Joe Setting agreed that having someone who is well-known in Delaware to help with the cause is essential. The worst experience when his wife, Judy, had Lyme Disease was being told by a doctor that the Lyme Disease diagnosis was a ‘trashcan diagnosis’.

Bill Meredith recognized that the market is there for a vaccine with high efficacy and little side effects because the crisis zone runs from Boston to Washington DC.

The next meeting of the Task Force was set for Tuesday, February 3, from 6-8pm. The meeting adjourned at 8pm.