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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- February 3, 2015

The Lyme Disease Prevention Task Force was called to order at 6:10pm 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, Karen Panunto, Dr. Stephen Eppes, Dr. Kathy Spreen and Dr. Awele Maduka-Ezeh. Members participating via conference call included Danielle Blount, Linda Wolfe, Dr. Heather Hirst, and Dr. Kathryn Wotman. Additional participants included Paula Eggers, Infectious Disease Epidemiologist Dept. of Public Health, William Kirk, Vice President Highmark Delaware, and George Meldrum, Senior Policy Analyst Nemours Foundation.

The committee reviewed the minutes of the first meeting. Speaker Schwartzkopf motioned to approve the minutes as amended by Judy Setting. Sen. Ennis seconded and the motion was approved unanimously.

Dr. Spreen gave a presentation highlighting why Lyme Disease is so complicated. This multi-system disease can be disabling, and there is a lot of inaccurate information written about the disease. Dr. Spreen read over 10,000 articles to write her book, "The Compendium of Tick-Borne Disease". Many of the scholarly articles written about Lyme Disease are contradictory or just wrong.

Commonly patients experience a delay in diagnosis or a misdiagnosis of Lyme Disease as viral infection like the flu. Patients are often bounced from one doctor to another treating each symptom of the problem while not addressing the root, the underlying infection causing symptoms. Patients are often treated with disrespect and disdain. Some doctors refuse to diagnosis unless there is a deer tick present or a large target. Lyme bacteria are highly evolved to survive, making it difficult to kill completely. The bacteria can remain dormant in the body and flare up once conditions improve. Neuropsychiatric symptoms are common and patients experience cognitive deficits. Patients cannot focus for more than a few minutes at a time and have problems with memory and processing. The importance of doctors understanding the science of this bacterium can help them to prescribe treatment. Chronic, persistent and long-term side effects of Lyme Disease are seen in 30-40% of patients with a genetic predisposition. 7-10% of people are completely flattened and debilitated by Lyme Disease.

Dr. Spreen reviewed in detail the many myths she has identified about Lyme Disease, a few include:

- Myth: Patient must have a bull's eye rash to have Lyme Disease.

Only 7-20% of patients will have the target lesion. About 30-40% of patients will have a maroon oval and most will have no rash at all. If you only diagnose Lyme Disease when a patient has a rash you will miss half the cases.

- Myth: You do not need to worry about a tick bite if the tick was attached for less than 24 hours.

It is true that the longer the attachment the more likely the transmission. So the likelihood of transmission goes down with shorter transmission times, but it does not mean you can rule out Lyme Disease if the tick was attached for less than 24 hours. It is also difficult to know exactly when a tick attached to the body.

- Myth: You need a positive lab test to have Lyme Disease.
The Center for Disease Control (CDC), National Institutes of Health and Federal Drug Administration agree that you have to diagnose Lyme Disease based on clinical symptoms not the lab test. Health providers and insurers cannot rule out Lyme Disease because of negative lab tests.

Dr. Spreen explained that Delaware is a tick paradise with the perfect habitat for ticks. Ticks thrive on the edges of farm land, beach grass and suburbs. Delaware also has a deer population that is exceeding capacity. In Delaware, patients have very few state providers and many providers do not believe in chronic Lyme Disease. There is no organized advocacy group in Delaware. Many Delaware patients reach out to the Lyme Disease Association of the Eastern Shore of Maryland.

Dr. Spreen identified healthcare provider education as an essential key to improving Delaware's management of the disease. Other proposed actions included:

- Shorten diagnosis periods to prevent the acute condition from getting out of control.
- Educating the public on symptoms and treatments, especially vulnerable populations who are desperate for treatment and may seek out unscrupulous practitioners.
- Protecting providers who may be afraid of treating Lyme Disease or even learning more about the disease because of the controversy. Ensuring that the State Medical Board is not going after practitioners who do not follow traditional Lyme Disease guidelines.
- Inform the public that they do not need a positive Lyme Disease test to be diagnosed with Lyme Disease.
- Improve insurance coverage for long-term Lyme Disease treatment. Coverage has been denied by some providers if patients did not have the positive lab test.
- Prevent transmission by better controlling deer and tick populations and treating pregnant women who can pass the disease to their child.

Dr. Spreen explained that the CDC reported cases for Delaware are only reflecting cases with positive lab tests based on surveys and insurance claims. Rep. Short asked what the recommendation would be for properly diagnosing patients. Dr. Spreen felt that the test was a piece of the diagnosis but that you cannot rule out Lyme Disease if the test is negative. She

wants to see treatment start earlier. Ideally, the blood culture would be the first test taken, but it is expensive and some doctors feel that there are too many positive with the blood culture. Dr. Spreen felt that if the test is going to be used doctors, they need to be more educated on the validity of the test.

Dr. Maduka-Ezeh shared that Delaware has consistent reporting procedures unlike other states and introduced Paula Eggers who tracks the data each year for the State of Delaware.

Brian Bennett, a Lyme Disease patient, shared his experience with insurance not covering his treatment because a doctor did not diagnosis him with Lyme Disease. He travels to Baltimore to see an out-of-network specialist.

William Kirk with Highmark Blue Cross Blue Shield shared his background. He explained that he mission of Highmark to improve the health of the community and participated in the meeting to better understand the scope of the problem as it relates to health insurers.

Dr. Eppes shared that education at for all medical professions, including doctors, nurses and school nurses, is needed. When medical professions are shown the right thing they will do it; they just need the right information to work from. The Medical Society expressed its support of medical professional education on Lyme Disease.

Dr. Maduka-Ezeh shared her appreciation for the passion and energy in the room and asked the committee to focus on the low hanging fruit including public awareness and provider education.

Sandy Reyes noted that Lyme Disease has not received federal funding for research. In order to receive funding for research the disease would have to be designated as a “listing” through the U.S. Department of Defense by the Delaware congressional delegation. Amyotrophic Lateral Sclerosis (ALS), for example, has been designated approximately \$15 million through this funding stream.

William Meredith reviewed the 2007 proposal by the Department of Natural Resources and Environmental Control (DNREC) and the Department of Health and Social Services (DHSS) with the committee. The Department of Public Health would provide an aggressive outreach program to healthcare providers and the public, while the DNREC would work on controlling ticks by identifying hotspots and performing tick related research and application. The proposal emphasizes awareness, deer population control and alerting the public to high infestation areas. There is also the ability for DNREC to use small scale pesticides to control tick populations.

George Meldrum explained that Lyme Disease has not been as prominent an issue the way obesity and smoking has been for children. He planned to discuss with the Nemours Foundation what they are doing on this issue and who would be interested in doing more. He was interested in the impact Lyme Disease has on children. Marilyn Williams with the Lyme Disease Association of the Eastern Shore of Maryland stated that children are the most susceptible.

Linda Parkowski asked about legislation in other states that had failed because advocates fought against them. Marilyn Williams explained that in Maryland a rogue member of the advocacy

groups created an ugly situation in the Maryland state legislature. Linda Parkowski reiterated the key issues to be addressed were protecting physicians, funding research and mandating coverage. Speaker Schwartzkopf gave an overview of the categories of action identified by the committee, Education, Prevention, Diagnosis and Treatment, Health Insurance Coverage. He suggested reaching out to Delaware's congressional delegation to request funding from the federal government. The Speaker emphasized the importance of having the right people at the table to get results.

Rep. Short asked about the exact lab test costs. Marilyn Williams shared that the Western Blot test can range in price from \$150- 200 and a blood culture from \$500-600. Speaker Schwartzkopf reviewed the legislation of other states and noted that Maine went beyond just education requirements and required health coverage for the detection and treatment of Lyme Disease.

Dr. Spreen reminded the committee that not all labs are created equally so moving from the traditional test to the blood culture is not a silver bullet. Doctors are using the CDC surveying guidelines as the basis for Lyme Disease diagnosis. Dr. Spreen noted that this is disease is actually quite young, 40 years old, and there is not enough good data to use. Dr. Desmond Kahn suggested allowing treating physician to make the decision on diagnosis by evaluating the symptoms.

Speaker Schwartzkopf highlighted the cost difference between patients treated quickly and patients who are not diagnosed. Patients receiving treatment earlier have significantly reduced costs in the long run. Marilyn Williams added that in 1998 the CDC quantified the cost of Lyme Disease if treated early as \$400 while the untreated cost is \$60,000.

Marilyn Williams highlighted the importance of testing for co-infections that come along with Lyme Disease not just the Western Blot test. These tests for co-infections include babesia microti, babesia duncani, bartonella hensalae, bartonella Quintana, mycoplasma fermentens and mycoplasma pneumonia

Dr. Maduka-Ezeh said that the CDC is not just looking at the tests when compiling case data but also counting diagnosis based on Erythema Migrans rash. She noted that the additional testing will increase costs without adding value. She felt the group should start smaller.

William Meredith did anonymous survey of Fish and Wildlife employees earlier in the month. Of the 100 employees her surveyed, 61 said they routinely work in the field. Of the 61 who work in the field, 11 had been diagnosed conclusively for Lyme Disease and 15 had suspected Lyme Disease. That is 41% of the employees who are working in the field. Of office workers with occasional outdoor recreation, 13% conclusively had or suspected having Lyme Disease.

Lisa Ray, a Lyme Disease patient, shared her experience with hundreds of hospital stays and four surgeries. She has been denied disability coverage four times. Elise Kenton, Lisa Ray's mother, shared her perspective as a caregiver.

Marilyn Williams explained the history of the Lyme Disease Association of the Eastern Shore of Maryland. It was started by mothers who couldn't get help for their children. The organization

focused on community awareness and is now trying to bridge the gap with the medical community. She shared the upcoming events of the association and noted that psychiatric manifestation of Lyme Disease has increase in the last year. The Association has found that peer pressure has been a barrier to doctor education. The Association has made videos of conference speakers available online. Disability coverage is also a problem for patients struggling to keep their jobs while debilitated. Since Lyme Disease is not understood as a chronic debilitating disease, patients are not getting approved for disability coverage.

Dr. Desmond Kahn thanked the co-chairs for this hopeful effort. He was infected in 1989 and was re-infected in 2013 producing a positive blood test. He took antibiotics for a month which helped eliminate symptoms, but after he went off antibiotics the symptoms can back. Since Lyme Disease can remain in the body dormant this is not surprising. But, his doctor would not prescribe antibiotics again because the doctor felt if symptoms had gone away for a time the Lyme Disease was killed. Dr. Kahn wants to see doctors who treat Lyme Disease effectively protected by the law and that poor guidelines from infectious disease associations are addressed. He recommended the documentary "Under our skin". Judy Setting and her husband provided copies of the documentary to the committee.

Brian Bennett suggested getting a Lyme literate doctor (LLD) in Delaware. Marilyn Williams shared the challenges with doctor payment structure for Lyme literate doctors. Your first visit with a LLD is extensive, potentially two hours long. Doctors need a full history and a comprehensive meeting. Doctors cannot take the regular payment for a typical doctor visit that lasts ten minutes. But the insurance payment structure is not properly compensating for these important longer visits.

Rep. Short stated that he would not be satisfied if the committee just went after the low hanging fruit. With such a large group brought together and focused on this issue, now is the time to aim high. He reminded the committee members that they are the best advocates for new policies. Speaker Schwartzkopf added that the more legislators the committee can expose to this information the better chance at accomplishing change.

Marilyn Williams added that the goal with public education is not to scare people but to empower people.

Sen. Ennis reminded the committee that they are tasked with reporting back recommendations and to coordinate efforts to see through Lyme Disease prevention efforts.

The next meetings were set for the evening of Tuesdays March 3, April 7 and May 5. The meeting was concluded at 8:30pm.