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Testimony before the Pennsylvania Senate Health and Human Services Committee and Aging and Youth Committee on the impact of Lyme Disease on the Commonwealth and an Update on the Lyme Disease Task Force Report

Dear Members of the Senate Health and Human Services Committee and Aging and Youth Committee:

I am pleased to be able to represent the Pike County Tick Borne Disease Task Force in testimony before the above committees on the impact of failure of the Commonwealth to implement the recommendations of the State Tick Borne Disease Task Force. The Pike County Tick Borne Disease Task Force was formed in 2015 to deal with what we perceive to be an epidemic in Pike County of Lyme disease and its co-infections. One member of the State Task Force, Dr. Robert Ollar, was one of the founding members of the County Task Force. From the outset, the goal of the Task Force was to develop County-wide Programs to educate, alert and support citizens of the County in dealing with Tick-Borne Diseases. Our focus has been prevention, early treatment and programs and support for chronic sufferers. We have worked closely with the Pennsylvania Department of Health County Health Nurse, Cooperating Physicians in the County and cooperating Infectious Disease Doctors outside of the County in developing recommendations to our citizens in these three (3) areas of concern. We also work closely with East Stroudsburg University in their development of a program for harvesting ticks and testing them for various coinfections that are known at this time. As a result of the interactions described above we have developed certain educational materials which have been attached to these remarks. We welcome your review of these materials and would welcome any questions that you might have on them.

Although my remarks could address a number of issues related to Tick Borne Diseases, we have decided that we would address two (2) key issues that directly relate to implementation of the State Tick Borne Disease Task Force report. They are mandatory Health Care Giver Education and Mandatory Reporting of Tick Borne Disease Cases. The State Task Force Report suggests

and recommends the development and implementation of an initial and ongoing education program for healthcare providers. It is our view that a comprehensive program should be mandatory for emergency room physicians, infectious disease physicians, internists, general practitioners and pediatricians. Pediatricians are very important since it appears that the incidence of infections in young children is significantly higher than that in the general population. In the two (2) years the Pike County TBD Task Force has been in operation, we have been made aware of numerous cases in which physicians have misdiagnosed TBD's, ignored the requests of patients or their parents to test for TBD's, failed to retest when symptoms developed after an initial negative testing, have failed to order molecular testing when symptoms persisted and antibody testing was inconclusive and in prescribing medication for a much shorter course than is currently recommended. We have also seen a number of cases in which first responders to tick bites such as emergency room doctors/nurses and school nurses have removed ticks with no follow up.

It is our belief that mandatory continuing medical education for physicians in the field as outlined above must be implemented to protect our population. This should include specific school nurse training for the removal of ticks, notification to parents, and recommendations of follow up testing, treatment and care. Protocol for school nurses should be uniform and form documents should be made available to assist nurses in dealing with tick bites and the encouragement to parents to have both the tick and the child tested for the potential need for follow up care.

Pike County sits on the Delaware River and borders both New York State and New Jersey. Ticks do not recognize state borders. We have no hospital in Pike County. Many of our residents, whether part time or full time, obtain medical care in other states. We view it as mandatory that inter-state cooperation for the reporting of cases be implemented. We have observed in the official records of the Dept of Health an underreporting of the number of cases of tick borne illness related cases for Pike County. This can be attributed to several factors, namely: a) many of our cases of tick borne illnesses are treated by Physicians in the neighboring states New York and New Jersey (these doctors located in other states are not required to report their cases to the Pa Dept of Health), b) many of our victims of tick borne disease are victims of tick borne pathogens that are not yet included in the official Dept of Health Reportable Diseases List, c) many of the doctors are not scanning non-Lyme disease pathogens that are also carried by our local ticks. One of our Pike County Physicians reported that their own office treated more patients than the total cited in the official Pa Dept of Health Statistics for Pike County. This underreporting of the problem has lead to misleading information related to the extent of Tick Borne Diseases in Pike County.

Tick existence is independent of official residency status so Inter-state cooperation is necessary in order to assess the true nature of this epidemic. Data from the states that border Pennsylvania is imperative. Out of state doctors are called upon to treat Pennsylvania tick disease afflicted patients who have crossed state lines to seek treatment. This is especially true for counties that do not have hospitals. Interstate cooperation will provide a better understanding of the incidence of this epidemic. It will also ensure improved treatment that will be linked to epidemiological numbers that actually reflect the real patient case load, and will justify that appropriate State support is provided to programs that deal with the ongoing Tick Borne Diseases Epidemic.

The list of mandatory reportable diseases in Pennsylvania must be updated to include Tick Borne diseases and all coinfections. In the absence of accurate data, the evidence that we have as to the scope of the epidemic in Pike County is anecdotal. I have compared it to people that I knew who lost their lives in 911 or people who were related to people that I know who lost their lives. I have also compared it to the opiate addiction and the HIV epidemic a few decades ago. Once we compare the number of people that we know who have been diagnosed with Tick Borne Disease or have members of their immediate family who have been diagnosed with Tick Borne Disease, the prevalence of these cases far exceeds all of these epidemics in Pike County. I myself have been diagnosed as positive for Tick Borne Disease. The number of people that I personally know who are suffering from chronic Tick Borne Disease is staggering. In an effort to locally address this population, the Pike County Tick Borne Disease Support Group holds support meetings on a weekly basis to attempt to aid these patients. Many of these patients suffer from neurological Tick Borne Diseases which is so debilitating that people have lost their jobs or have been unable to complete their educations. Since the Task Force report was written in September of 2015 and since the creation of the Pike County Tick Borne Task Force, we have lost our County Department of Health Nurse. She was essential in obtaining information relative to cases of Tick Borne Disease and assisting physicians' offices with follow up treatment.

Although it is somewhat outside of the scope of what I indicate in my testimony, we are very concerned about insurance policies in Pennsylvania not covering all necessary laboratory testing for all of the appropriate Tick Borne Disease coinfections. Although legislation has been proposed to deal with treatment and insurance, it does not currently address laboratory testing. Many plans have refused to pay for molecular testing which is necessary to diagnose some coinfections.

Thank you for this opportunity to present these remarks to the Committee and I would happy to answer any questions if I can.

Very truly yours,

PIKE COUNTY TICK BORNE DISEASE TASK FORCE
JOHN H. KLEMEYER, ESQUIRE

Enclosures