

**Testimony to the
New York State Senate Task Force on Lyme and Tick Borne Disease and
The Senate Standing Committee on Health**

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Presented by:

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Current Status of the Epidemic of Tick-borne Diseases in Stony Brook.

Good morning. My name is Dr. Luis Marcos and I am the Director of the Adult Lyme and Tick-Borne Disease Center at Stony Brook Medicine. I am joined by my colleagues Dr. Christy Beneri, Assistant Professor of Pediatrics, Division of Pediatric Infectious Disease at Stony Brook Children's Hospital and Dr. Susan Donelan Assistant Professor of Clinical Medicine, Division of Infectious Diseases at Stony Brook Medicine.

I wish to thank Senator Serino and Senator Hannon for hosting this hearing to help develop policies that will enable New York State to educate its residents and protect them from the dangers of Lyme and other tick-borne diseases.

Stony Brook University Hospital (SBUH) and Southampton Hospital (SHH) are the only tertiary medical centers in Suffolk County (SHH is now known as Stony Brook Southampton Hospital, thanks to the support of Senator Hannon), which is an area in the US with an abundance of ticks. Review of our SBUH electronic medical records (EMR) highlights the large numbers of cases of Lyme disease in our patient population. Specifically, 1,026 Lyme cases (based on ICD codes) were reported in our EMR for the period between 2010-2016. In that time, a total of 284 patients required hospitalization. In Pediatrics, we see inpatient admissions for Lyme disease as well, including Lyme carditis and Lyme meningitis. Pediatric Infectious Diseases Division also sees up to 25 patients monthly for outpatient referrals for Lyme disease and other tick-borne infections during the height of the tick season.

For other tick borne diseases, we have admitted 15 and 11 cases of Ehrlichiosis and Anaplasmosis, respectively, to SBUH between 2014 and 2016. In these cases, polymerase chain reaction testing (PCR) was used to detect the genetic material (DNA) of the bacteria in the bloodstream. These diseases can also be diagnosed by serology (antibody tests).

The limitations of the antibody-based test is that it requires, in most of the cases, a repeat blood test in 3-4 weeks to confirm the infection; and, the test is less specific because of cross-reactivity, which can cause a falsely positive test result. In our experience the PCR diagnostic test is not always ordered during acute disease (when it is the most helpful), and some patients do not come for follow up testing because they may not have insurance, or they feel better and no further medical attention is needed. This explains why number of cases may be underreported. In Pediatrics, the convalescent titers were found to be very useful for diagnosis, given the higher compliance with medical care from this population.

With regard to Babesiosis, we recently published a series of 62 adult cases at SBUH from 2008 to 2016, one of the largest series of cases reported to date in the literature. Since then we have seen several cases of complicated Babesiosis, including a case in a pregnant patient who presented with significant anemia, and an elderly patient who presented with spontaneous spleen rupture, a rare but serious complication of this disease. In Pediatrics we published a case of congenital Babesiosis and have seen another congenital case since, in addition to a severe case in one of our oncology patients. Patients with Babesiosis can present with non-specific symptoms and they usually do not have to have a fever. The diagnosis is only made if clinicians consider the infection and request the appropriate test.

According to the *Final Report of the Suffolk County Tick and Vector-Borne Disease Task Force* in 2015, Suffolk County reported for the year 2014: 231 cases of Lyme disease, 67 Ehrlichiosis, 46 Anaplasmosis and 197 Babesiosis. The trend on the number of cases in all these tick-borne diseases has increased from 2010 to 2014. We believe the true number of cases is higher than the officially reported.

Given the number of tick-borne diseases we see at our facilities, the Division of Infectious Diseases has recently announced a Tick Borne Disease Referral Clinic (https://medicine.stonybrookmedicine.edu/medicine/infectious_diseases/tick_clinic) in order to provide a much-needed service to the local medical community and residents of this county.

Our Pediatric Infectious Diseases colleagues also see tick-borne diseases referrals: <https://www.stonybrookchildrens.org/lyme-disease> or call 631-444-KIDS (5437)

The Gaps on Tick-borne Diseases: Diagnosis and Education

As a tertiary care center with expertise in tick-borne diseases, we receive many referrals and can be an important resource for local providers via education (prevention, diagnosis and treatment) about Lyme disease and other tick-borne diseases. Support (such as help lines and technologies to provide internet based consult support) are needed to develop a state-of-the-art educational center.

A major challenge we encounter is the diagnosis of early Lyme disease by serological testing, since these tests can be negative in about 60% of early cases and if treated promptly, early conversion may be aborted. Thus, understanding the clinical signs and symptoms of Lyme disease is important for appropriate test ordering and treatment. In addition, understanding the

epidemiology and ecology of ticks is important. Specific to Lyme disease, the time of tick attachment is a key component of risk of transmission and should guide early intervention. With regards to time-sensitive attachment and transmission of the other tick-borne infections, less is understood and thus remains an area ripe for further study and potential for intervention.

Lyme disease in children has an excellent prognosis. The spectrum of disease in children, like adults, includes early localized and early disseminated disease as well as late disease; however unlike adults, encephalopathy and polyneuropathy are uncommon in children. Understanding Lyme disease in different patient populations is also important.

Another significant problem is the lack of understanding of testing methods across the spectrum of health care providers, specifically the rationale for two-tier testing; the existence of non-specific cross-reactive antibodies; and the fact that antibodies represent a humoral response, which may stay positive for years and cannot necessarily be interpreted as untreated *Borrelia* organisms. Diagnosis that does not follow CDC criteria can confuse both the patient and the practitioner. In regards to treatment, SBUH follows mostly established guidelines published by the Infectious Diseases Society of America and the Committee on Infectious Diseases of the American Academy of Pediatrics. Prolonged use, as well as use of antibiotics when not indicated is dangerous and can potentially cause harm. These practices can lead to adverse potentially life threatening complications such as *Clostridium difficile* colitis, as well as sepsis by an infected central venous line. Unfortunately, we have seen several cases at SBUH where patients have presented with these complications. Additionally, prolonged use of broad-spectrum antibiotics can promote colonization with resistant microflora in patients as well as in their family members. This is a tremendous concern, as we have a national epidemic with emerging multi-drug resistant bacteria.

To foster the practice of evidence-based medicine, the Infectious Diseases Society of America (IDSA) proposed case definitions for Post-treatment Lyme Disease Syndrome (PTLDS) [IDSA guidelines 2006]. PTLDS, which describes a group of symptoms including chronic fatigue, unspecific generalized pain and neurocognitive deficits, is reported in about 10% of patients who had Lyme disease. Overlap with other diseases can occur and underscores the need to systematically study outcomes of treatment in clinical trials. Research is needed to better understand potentially debilitating symptoms related to Lyme disease, which occur or persist after proper antibiotic therapy. Such symptoms may also occur in patients who did not meet diagnostic criteria for Lyme disease in the first place. Clinical research and especially standardized clinical trials are required to tackle these issues. SBUH could serve as an ideal center to lead such trials.

Lastly, we also need to understand Lyme disease in the context of co-infections with other rick-borne pathogens, because patients with Lyme and Babesiosis may have worsening symptoms that may last for several months. Babesiosis, which has a longer incubation period than Lyme or other tick-borne diseases, may present later and could, therefore, not be diagnosed when the patient has acute Lyme disease. This is of particular importance as the antibiotics that treat Lyme and some of the other tick-borne infections will not also treat Babesiosis. Several distinct tick species exist in our communities and we work closely with the Suffolk County Department of Health to remain up to date on changing tick epidemiology and emerging infections. An example

is the Lone Star tick, which has historically been prevalent in the southern states. This tick transmits Ehrlichiosis, which is now often diagnosed in our patients. Also there is some clinical indication that patients bitten by this tick may develop IgE antibodies to alpha-gal, which results in an allergy to red meat. Collaboration on research in these areas is critical.

Stony Brook University constitutes a premier research institution, with NIH funded investigators in Lyme disease diagnosis, investigators invested in clinical vaccine and diagnostic kit development, as well as board certified infectious disease and primary care physicians who provide excellent clinical care to a patient population at risk. We have a loyal patient population and we are committed to continue to grow as a center for research excellence in Lyme disease and other tick-borne diseases.

Once again, thank you for the opportunity to share this information. Dr. Beneri, Dr. Donelan and I would be happy to answer any of your questions.