Martin J. Wilson

Oral presentation before The New York Senate Task Force on Lyme and Tick-Bourne Disease

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My name is Martin J. Wilson. I am 56 years old. I am a self employed title insurance agent. Doctors first suspected that I had Lyme disease in September of 2009. By this time I had been feeling poorly for several months. They ran a standard western Blot test, which came back negative, and they took me off the antibiotic that they had prescribed. I wasn't conclusively diagnosed with Lyme until October 2015. 8 years, over 25 doctors, including 5 neurologists, 6 internists, 4 infectious disease specialists, 2 rheumatologists and 2 cardiologists, long term oral antibiotics, intravenous rocefin, and IV/IG protocols, and every day, every single movement is painful. Slightly more than half of the doctors concluded that I have Lyme. Most are unable to help. All of my organs are inflamed, my immune and nervous systems are compromised, and I am in pain.....constant pain. All this, primarily because the Western blot test is approximately 44% reliable and doctors are uninformed.

It is not my purpose to stand here and cry that I might have been diagnosed earlier, treated earlier and perhaps enjoyed a better outcome. Unfortunately, this nightmare of mis-diagnosis is all too prevalent. What about the child that gets bitten this week? Everyone here recognizes that early treatment results in better outcomes. Without easy access to adequate testing many more will be doomed to my fate. I am fortunate to have good medical insurance, have the flexibility in my work schedule and the financial resources to finally arrive at a definitive diagnosis. Most people don't enjoy these luxuries.

The western Blot test is approximately 44% reliable. That's 56 missed cases out of a possible 100. That's a failing grade in anyone's class. Those are worse odds than flipping a coin for a diagnosis. This test was designed for statistical reporting to the CDC, not for diagnosis. The test measures a patient's antibody response to the disease. This essentially means it sees the shadow of the disease, not the disease itself. What happens when the test is given, and it's "HIGH NOON" in the patient's body? It casts no shadow. The patient is mis-diagnosed and doomed to suffer. It is noteworthy that three other states have enacted legislation requiring doctors to inform patients IN WRITING that a negative western blot does not rule out a diagnosis of Lyme infection. The test is that bad, yet doctors rely on it.

Every single test in the USA is based upon one copy of one Lyme organism, so it's usefulness in identifying any other strain of Lyme is limited. It is widely recognized that certain vital components of the test are not included, namely OSP A, OSP B and OSP D, among others. In 1994, Dr. Patricia Coyle of Stony Brook co-authored a paper entitled "Early and Specific Antibody Response to OSPA in Lyme Disease. The conclusion reads: "a specific antibody response to OSP A occurs early in Lyme Disease. This is likely to have diagnostic implications". Drs. Coyle and Schutzer developed a diagnostic test based on OspA back then. Currently, George Mason University has developed a urine test, using nano trap technology, but still based upon this most prevalent indicator of Lyme infection, OspA. Dr. Benjamin Luft of Stony Brook has developed a much broader assay based upon the most common proteins

present in ALL strains of Lyme, including OSP A, OSP B and OSP D. This has been known for 25 years and we still await satisfactory testing.

Polymerase Chain Reaction testing, essentially a DNA test, is on the cusp of being widely available and affordable. The Oxford Nanopore system promises to enable PCR based testing from a desktop computer in your doctor's office. It is currently being tested around the globe, as well as aboard the international space station. There are numerous laboratories across the country that are permitted to furnish various tests in 49 states, but not permitted here. Why not New York? Or better yet, we have Stony Brook, Cornell, Binghamton, Columbia and many more. We are New York, the epicenter of the financial world, as well as the epicenter of the Lyme epidemic. Why should the leading research be at Johns Hopkins, or Tulane or George Mason? This is our fight. We should have the funding here at our disposal to utilize in our own state, to provide testing that meets our criteria and standards. All of these technologies can and should be embraced to assist better and earlier diagnosis. At this time, no single test is foolproof. But used in conjunction, these tests can certainly improve upon the current 50% failure rate. The citizens of New York deserve better.

The CDC Western blot measure 10 bands. Currently, Stony Brook Lyme Disease Laboratory tests for 27 antibody bands, including the additional bands mentioned previously, but it only reports them if requested. I was told that approximately 30% of doctors request such additional data. That means 70% of those tested receive less information than is readily available. The patient is paying for the test. Aren't we entitled to our monies worth? It's like bringing your car for inspection and being allowed to drive away with no brakes. This information is crucial to an early diagnosis.

Stony Brook has these records going back many years. It is of vital interest to make this data public. We could then get true picture of the extent of this epidemic. I am sure that MS, ALS , Alzheimer's and autoimmune researchers would be interested to know how many of their subjects have had exposure to Lyme. Anecdotally there are many connections, but without hard data, such connections are meaningless. How many people have Lyme? We don't know. How many people die of heart disease or brain disease as a long term result of Lyme? We don't know. In the information age, this is totally unacceptable. It is obvious that New York State must act independently, at least at first, to clearly identify the nature and extent of this issue. The only way to exemplify our need for Federal funds is through hard data, the collection of which is one of the mandates of the 2014 report of this Task Force.

Yes, I read the report. Senator Hannon, you and the other Task Force members are to be commended for enacting legislation which protects Physicians, and thereby patients.

In conclusion, I request, implore, demand and humbly beg, that this Task Force and the legislative body that it represents, bring to bear all of their resources to implement the following:

1. To promote the use of Stony Brook Lyme Lab for western Blot tests, rather that private commercial labs, and to educate and instruct Physicians to avail themselves of all of the information available from such tests. Additionally, in cases where these tests are negative, but Lyme still seems likely, other tests should be performed, perhaps based upon Dr. Luft's assay.

2. To immediately collect and make public, all available data from Stony Brook. I believe the private sector can then use this data to solicit Federal Funds for research and development of better tests and treatment protocols.

3. To retrain Physicians on the latest developments, testing and treatment protocols for Lyme Disease through their routine Continuing Education requirements and to promote early prophylactic treatment in cases where Lyme disease is suspected or probable.

The person who becomes infected this weekend deserves this protection.

Thank you for your attention.