

Testimony for TICK Act Field Hearing
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Thank you Senator Collins, as well as to the esteemed members of this panel. I am honored to speak about my experiences and frustrations as a physician treating patients with tick-borne disease. No other illness has been as intellectually challenging to properly diagnosis and manage as Lyme. The more I learn about this disease the more questions I have, and the more I realize we have just scratched the surface of how complex the answers are. Hopefully your work on the TICK Act will move the research forward and provide more hope and more help to Mainers, and to the worldwide public health.

As a young resident at Maine Medical Center, I felt I was well-trained in the classic signs and symptoms of Lyme Disease. We were taught to look for the bulls-eye rash, the flu symptoms outside of flu season, the joint pain. Like my colleagues I treated these acute cases with a short course of antibiotics. However, I began to see more and more patients who didn't fit the typical scenario. They never remembered a tick bite, they never had a rash. Their blood testing was negative for tick-borne illness. They grew sicker and sicker despite seeing multiple specialists. I had to become a detective doctor to figure out how to help these people. I needed new tools for my tool box.

I began attending conferences run by the International Lyme and Associated Diseases Society (ILADS) and learned that there was more to the story than the basic model I was taught in medical school. I learned there were differing opinions and conflicting guidelines between the Infectious Diseases Society of America (IDSA) and ILADS. In short, IDSA states that Lyme Disease is easily diagnosed with standard two-step blood testing and easily treated with a short course of antibiotics. If patients' symptoms persist it is because of the damage already done and not because of a lingering infection. ILADS' view is just the opposite: the standard testing may not be accurate because of how Lyme can fool the immune system, and a short course of antibiotics may not be enough to eradicate all organisms in a person's body. ILADS feels that chronically ill individuals need a more comprehensive and long-term therapeutic regimen to treat their real disease, and not just be dismissed as suffering from "the aches and pains of daily living".

Here we had two groups of very smart doctors, both wanting to help their patients, at loggerheads over how to diagnose and treat Lyme Disease. This conflict left me and my patients in the middle searching for solutions. Now I've got a Master's in Public Health and a Master's in Medical Sciences so I love research. I dove into the literature from the standpoint of an open-minded skeptic. I read both sets of guidelines. I read the peer-reviewed journal articles supporting both sets of guidelines. I looked into who the authors were and who was paying for their research. In the end, I tried both sets of guidelines on my real-life patients to observe which approach worked best.

I found there was room for both the IDSA and ILADS solutions depending on the situation. The IDSA approach works well for acute, classic Lyme Disease. If a person has a strong, healthy, robust immune system at baseline then the testing should begin to turn positive after 2-3 weeks of infection. Fortunately this infection is usually very easy to treat with a short course of antibiotics *if you catch it early*.

Unfortunately, if you don't catch it early, this smart little spirochete begins to go through its own life cycle. It changes its shape and hides from the immune system, causing inaccurate, false negative blood testing. It creates a physical barrier called a biofilm that protects it from antimicrobials and from your own white blood cells. We are discovering what are called 'persistor cells' that are resistant to antibiotic therapy. They can remain dormant in a human body for months or years before they wake up again.

In the unfortunate individuals who become chronically ill, multiple systems are affected. There is a complex interplay of genetic factors, inflammation and immune dysregulation, hormonal imbalance, neuroendocrine disruption and neuroinflammation leading to cognitive deficits and psychological illness, gastrointestinal dysfunction causing nutritional insufficiencies, which create metabolic imbalance and poor mitochondrial function, leading to the chronic fatigue that many describe. As I learned, a few weeks of antibiotics are not enough to heal these complex cases.

The ILADS approach works better for these types of patients. It is an individualized, head-to-toe, integrative method of figuring out what is broken, what are the root causes of the illness, and how to help that person heal from the inside out. It's certainly not a perfect approach. Sometimes it requires long-term antibiotics that have their own risk of side effects. It's complicated and it takes a lot of the practitioner's time to do the detective work. It also takes a lot of the patient's time and energy and healthcare dollars to walk that road to recovery. These people need a lot of support to get them through the bad days. Eventually they celebrate more and more good days and move forward to remission.

To summarize, I have learned that there is no perfect set of guidelines, no one-size-fits-all algorithm that works for every case in the real world. The testing is imperfect. The medications don't always work. Some people get better right away, and some people develop problems that linger for years. The classic presentation of Lyme Disease that physicians learn about in medical textbooks doesn't always apply, because this little bug forgot to read the textbook.

We need more answers, Senator Collins. How can we prevent the illness in the first place? How can we improve the accuracy of the testing? How can we tell which treatments will work best, and how do we know when to discontinue a regimen? Your excellent work with the TICK Act will hopefully help provide more answers to the doctors and patients out there dealing with tickborne disease. Thank you very much and be well.