

Esteemed members of the Public Health Committee:

I am a board certified Emergency Nurse who suffers from neurological Lyme with auto-immune phenomenon. Bill 368 particularly concerns me, as well as it does others who suffer from this insidious disease, Lyme disease is more prevalent than AIDS, and West Nile Virus combined. These are the only confirmed patients of Lyme disease who count in those numbers. There are many who go undiagnosed, or who are undertreated. It is a true epidemic.

This bill concerns having the DPH report all cases of Lyme, so that the CDC will be able to discuss standardization of treatment, and surveillance of symptoms. This starts at the LOCAL LEVEL! The problem is that each state has it's own laws, but I hope that the heart-felt testimony you hear today will convince you to assist us in this matter concerning quality of life, and sometimes the death of patients. Diseases that are infrequently seen, such as malaria or Q fever are reportable to the CDC, yet Lyme is the most common vector-borne illness in the U.S.!

The CDC requires testing by validated methods, and believes that only several weeks of treatment is necessary in most cases. The NIH also states that most patients respond well to antibiotics and have a "full recovery". These organizations rely on the IDSA Guidelines which promote short-term treatment as well. I was told, in fact by 2 Infectious disease doctors that 3 weeks of oral treatment was sufficient to cure my neurological Lyme. Thankfully, I did not listen to them, as my health rapidly declined.

There is much politicism in regards to Lyme, as knowledgeable doctors are in jeopardy of losing their licenses due to not following the CDC/NIH/IDSA guidelines. Surprisingly, when one calls 211, there is not a single Lyme specialist here in the state where Lyme was discovered! I was fortunate to find a Lyme-literate doctor who accepts insurance, but I have to be driven to MA. to get help.

Early treatment and diagnosis is crucial, yet standardized testing is often unreliable. Lyme disease MUST BE TREATED BY THE PATIENT'S SYMPTOMS, not by fallible testing. Gratefully I was knowledgeable early into my journey with Lyme, and after a negative Lyme test, asked my primary care doctor to order a PCR test( a test he had never heard of!).

There are new studies coming out of Columbia University, and Stonybrook that bely the limited studies done by the CDC/NIH/IDSA in regards to long-term testing. In the Monkey Study from Embers, 100% of the inoculated monkeys showed positive for Lyme after 4 months, although their blood tests were negative. In UNTREATED monkeys, 29% had negative Elisa tests for chronic Lyme and 71% had persistent Lyme upon necropsy : therefore a test with better efficacy would be the IFA(immunofluorescent assay) for example.

It has been over 40 years since Lyme was discovered here in our great state. I believe that with proper testing and reporting, this illness will get the national attention it deserves. More importantly, those who suffer with Lyme, or their loved ones will be able one day to see this disease eradicated.

Please consider that legislature starts at the local level, and that we have faith that our senators, representatives, and DPH will bring this to the forefront.

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