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HOUSE OF REPRESENTATIVES

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March 22, 2023

Testimony of Representative Dan Shagoury introducing LD 906, An Act to Ensure Physicians Receive Full Diagnostic Test Data **Concerning Tick-borne Diseases** Before the Health and Human Services Committee

Good afternoon Senator Baldacci, Representative Meyer and fellow members of the Joint Standing Committee on Health and Human Services. I am Representative Dan Shagoury, and I represent House District 55, which includes the communities of Hallowell, Manchester and West Gardiner. I come before you today to introduce LD 906, An Act to Ensure Physicians Receive Full Diagnostic Test Data Concerning Tick-borne Diseases.

Tick-borne diseases, including Lyme disease, babesiosis, anaplasmosis and ehrlichiosis, are a relatively new scourge in Maine. Even though it has been around for a while, Lyme disease was only formally identified in 1975, and testing and treatment are still problematic.

My own bout with Lyme disease is illustrative of the problems with diagnosis. Eight years ago, I became very sick – literally as sick as I have ever been in my life. High fever (104.5), pneumonia, chills, etc. But I didn't present "normally" for Lyme. I didn't have a rash, and I didn't know if I had been bitten by a tick, so my doctor was hesitant to test for Lyme. Eventually she did. I was found positive, given a three-week course of Doxycycline and I was back to normal.

My constituent, who you will hear from shortly, had a different problematic experience with Lyme testing. By Federal CDC guidelines, five dark markers on the right side of the test strip must be present to be considered positive for Lyme. Based on that guidance, most labs simply report back either "yes" or "no." The reality is more nuanced, and in her case, and others like hers, Lyme can be present with fewer markers showing positive than the federal CDC demands.

If Lyme disease is diagnosed early enough, as it was in my case, it can be treated successfully. If not, however, it can lead to chronic Lyme disease, which can be debilitating and very difficult to treat.

I will let her tell you her story, but she tested "negative" for three years and suffered through sickness and misdiagnosis until one of her doctors got the test results in full and was able to see that Lyme was present in her system after all.

That is why I sponsored this bill. It is not the intent of this bill to tell doctors how to practice medicine, but rather to see that doctors have all the information they need to make an accurate diagnosis for these diseases. This is as it should be. Information that will help a doctor make a proper diagnosis should not be withheld in the interest of simplicity.

I have included additional tick-borne diseases in this bill because they are often co-occurring and have similar diagnostic testing issues.

Thank you for your consideration. I look forward to working with you on this bill, and I will be glad to answer any questions.