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Good afternoon, My name is Abigail Ross, I live in Port Clyde, and I am here to testify in favor of LD 1688.

I am here today to talk about Lyme disease, specifically as it relates to LD 1688, which is a bill that has the potential to help prevent an unGodly amount of suffering among Maine residents. The fastest growing vector-borne disease in the country, nearly half a million people will get Lyme disease in the US this year. In Maine, 3,218 cases of Lyme were reported in 2024. For every reported case there are undiscovered ones, so the real number of Maine residents being exposed to the Lyme bacteria this year may actually be closer to 6,000 people, or more. Knox county, where I live, has the highest rates of anaplasmosis in the state, which has some of the highest rates in the country, meaning we are literally at ground zero for some of the most debilitating illnesses in the history of the world.

Lyme disease doesn't change your life, it takes it completely. It is an amount of suffering that cannot be imagined before experienced. You hear a lot of Lyme patients say it feels like "demonic possession," because the feeling of having this bacteria inside of you, causing encephalitis and myocarditis and chronic fatigue and extreme joint pain, can be compared to little else. It isn't human and the pain it inflicts is not on a human scale.

But, there is a growing world-wide body of research changing common misconceptions about Lyme disease. As I talk about shortly, the Global Lyme Alliance has compiled over 700 peer reviewed articles proving the borrelia spirochete, (the bacteria associated with Lyme disease), can survive in the body post antibiotics, creating a condition known as chronic Lyme disease. New research is emerging every day, and it is critical that this new information gets into the hands of the medical professionals in our state because they are the ones responsible for effective recognition, diagnosis and treatment of this condition. In the pages to come, I will talk about what chronic Lyme disease looks like in a typical Maine community. I will present some fascinating research linking tick borne illness to common neurodegenerative diseases for which a definitive cause is still unknown, such as Alzheimer’s, ALS, and MS. I will also talk about the limitations of current testing, something that is grossly misunderstood and present a new, more sensitive test that recently passed FDA approval.

But first, I would like to put some faces to Lyme disease statistics. What does all this look like in our actual communities? Why does it matter that our medical professionals receive training on the most current findings related to tick borne illness? Here is what Lyme disease looks like in the average coastal Maine community:

In St. George, both of my neighbors have contracted Lyme, but prevented it from becoming chronic by getting antibiotics in time. The neighbor catty corner to my house is having issues with vision loss, I believe, from a Lyme disease infection. We have two restaurants in town and bartenders at both have chronic Lyme disease. Two of the women who work at our tiny post office suffer with late stage Lyme disease and as a result deal with secondary complications like Hashimotos and Morgellons. Our former landscaper has a wife who is debilitated by Lyme and cannot work, which makes raising their children difficult and puts a lot of pressure on him financially. Our current landscaper has both a brother and a father suffering with chronic, late stage Lyme disease. My hairdresser woke up a few years back paralyzed from the waist down and dragged herself to her phone to call for help. She had been gardening the day before and got a tick bite that most likely transmitted not just Lyme, but also anaplasmosis. Luckily she was treated quickly and effectively. A friend a mile down the road believes his Atrial Fibrillation can be traced to a case of undertreated Lyme disease that he had years ago. Last summer, I hired someone to haul away a pile of wood from our property, and *he* had chronic Lyme because it had taken him over a month to get diagnosed originally. Last spring we hired a painter to come give a quote for our house. He showed up experiencing active palsy on one side of his face from an acute infection of Lyme disease. My mother is a quadriplegic, and since moving back up to Port Clyde a few years ago, one of her caregivers and two of her nurses have been individuals who have late stage Lyme disease. I went to the bank to close an account just three weeks ago and the woman who helped me said her brother in law has both Lyme and alpha gal syndrome, the disease that makes you allergic to red meat, (also on the rise), and her young niece has lost her youth to debilitating chronic Lyme disease. At a Walmart grocery pickup a month ago, I somehow managed to mention Lyme to the young man putting the bags in the trunk of my car and he said he too, has chronic Lyme. One of my closest friends here is an ophthalmologist. Last summer he had a patient in her 80s die very suddenly from Babesia right at Penbay Medical Center in Rockport. It took several days for them to figure out what was going on, and the damage had been done. A few years ago I posted a warning on our community Facebook page about the area where I had gotten into the nest of ticks that took my life as I knew it. Below that post at least 20 people commented about their experience with Lyme disease, just in my tiny town of population 3,000, and several of those people used the words "almost died" in relation to heart related conditions.

Where I am, this feels apocalyptic.

Our doctors and nurses and physician assistants are some of the most important professional members of society. But in a lot of cases, when it comes to emerging research, our healthcare professionals simply aren't being given what they need to make the right judgment calls when it comes to Lyme and the co-infections that often accompany it.

There is, in reality, a growing body of Lyme research, much of which has yet to be brought into the average medical school curriculum in this country. But it can be. And it *must* be soon, because here in Maine, entire communities are being set back by this growing, often silent, epidemic. The Global Lyme Alliance, for example, has a document where they have compiled over 700 peer reviewed articles proving that the spirochete borrelia burgdorferi (the type of borrelia bacteria most commonly associated with Lyme disease), *can* survive in the body post antibiotic treatment.[1] Many of these are hiding in plain sight at PubMed or the NIH database. Dr Alan MacDonald, a world renowned U.S. pathologist, "found the DNA of Borrelia in 7 out of 10 autopsy brain specimens from victims of Alzheimer's, (supplied by Harvard's Brain Bank). Using genetic sequences found in these specimens and Molecular Beacon technology he found the Borrelia DNA was

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[1] https://www.ilads.org/wp-content/uploads/2018/07/CLDList-ILADS.pdf

located at exactly the spots where plaques appear,"[2] which are the diseased areas of the brain tissue which are a hallmark of Alzheimer's).

In a new study, researchers at University of North Carolina found the Bartonella bacteria, also transmitted by ticks as well as fleas, in the blood of 65% of their test subjects diagnosed with schizophrenia, verus 8% in the healthy control group. 43% of participants diagnosed with psychosis had Bartonella DNA in their blood, compared to 14% of the control population. The director concluded, "As an infectious disease researcher, I believe that infection should be critically examined as a potential cause of diseases for which the cause is unclear or unknown."[3]

There is a Facebook group called Chronic Lyme: It's a Thing. I know there is a tendency to easily dismiss anecdotal evidence, or assume people are ignorant or confused, but this group now has 16,000 members and is growing. Every day there are *multiple* new members who come into the group with a diagnosis of fibromyalgia, chronic fatigue, MS or even ALS, who also have Lyme disease and wonder if maybe there is a connection. There is. I spoke with a woman who was told she was autistic her whole life. She treated and cured her autism at the age of 40, with antibiotics, because it turned out to be Lyme disease. This is not a small number of people. The documentary *Under Our Skin* follows the journey of a man who cured his ALS when he treated his Lyme. You see this all the time in the Lyme community. If you have any interest, I *highly* recommend visiting this Facebook group and searching for the words "MS" or "ALS" because you will be shocked to find hundreds and hundreds of people who turned those conditions around when they discovered they had Lyme disease, after many years of mistaken diagnosis.

There are a lot of common conceptions around Lyme that have turned out in the last decade, based on emerging research, to be incomplete. The misconceptions are affecting the ability of our healthcare professionals to intervene and treat tick borne illness in a timely and effective way.

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[2] Dr Alan B. MacDonald | The Lyme Dialogues Podcast

[3] https://news.ncsu.edu/2024/06/bartonella-dna-found-in-blood-of-patients-with-psychosis/#:~:text=A%20new%20study%20has%20found,than%20adults%20without%20these%20disorders.

For example, we are told that Lyme presents with a bulls-eye rash. According to Global Lyme Alliance, only 30% of tick bites transmitting Lyme present with a bulls-eye rash. We are told that Lyme is easy to diagnose and easy to treat. That can be true when it is caught very quickly, but in many cases, even 48 hours is too late, and treatment will need to be much longer than the standard 2-4 weeks as the spirochetes move out of the bloodstream and drill into muscle and tissue. The average patient who has been diagnosed with Lyme disease has seen between 4 and 12 doctors before getting their diagnosis. We are told that Lyme cannot be transmitted through pregnancy. However, my Lyme literate practitioner and many of her colleagues test the placenta and babies of their infected clients and frequently see transplacental crossover of the bacteria, in both placenta and newborn. Right now Children's National Hospital in Washington, DC is leading a pilot study, to "establish the groundwork needed for a larger study to determine the effect of in utero exposure to Lyme disease on pregnancy and early childhood neurodevelopmental outcomes."[4]

The current testing for Lyme is also inadequate. "We are told that the standard two tier testing at the hospital is 95% effective for detecting Lyme - in reality, the current testing was never standardized for late stage disease and is about 50% accurate. Lyme bacteria is only in the bloodstream transiently and at very low levels. This is one of the biggest challenges in diagnostics. When we detect other bacteria we are measuring tens or hundreds of thousands of bacteria and in Lyme disease you have to have the sensitivity to measure **10** bacteria. That's below the limits of sensitivity of currently available PCR tests. So currently at the moment, it is an immune based test. It's measuring your own immune system's response to the bacteria. But the bacteria has an uncanny ability to evade the immune response. So, you're trying to use immune based testing for an organism that is suppressing the immune system."[5]

In addition, current two tier testing using Western Blot and ELISA typically tests for **two** strains of borrelia, (Borrelia burgdorferi and Borrelia mayonii), when there are over 70 active strains of borrelia in the US, and nine that are routinely causing Lyme disease in this country now, including several here in Maine that aren't being

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[4] https://innovationdistrict.childrensnational.org/lyme-disease-in-pregnancy-and-infant-development/

[5] Documentary: I'm Not Crazy, I'm Sick. https://imnotcrazyimsick.com/

tested for, (B. afzelii, B. garinii, B. spielmanii). Many doctors don't know that even according to the CDC, these recommended tests were never intended for diagnostic purposes. In their own words, these tests were meant for statistical reporting purposes and diagnosis of Lyme disease should be done based on symptomatology. Additionally, in 1994, two bands (The 31 and 34 kDa bands), were removed from the Western blot test for Lyme disease because these proteins were used in the LYMErix vaccine, and they were causing false positive results in vaccinated individuals. To prevent confusion between vaccinated individuals and those with actual Lyme disease, these bands were taken out. That vaccine was discontinued in 2002, but the bands were never reintroduced. Just returning the test to its original design, and bringing those bands back in, would greatly improve the accuracy of current testing. [6]

But, good news. Recently a better, more sensitive test run by a lab in California called IGenex has passed FDA approval. This is something that doctors here in Maine should know: there is better testing available now, and it's likely to make its way into hospitals soon, with a little awareness and advocacy. This kit is more sensitive and reintroduces the bands mentioned above that were removed from the original test[7]. Any doctor in Maine should consider advocating for the use of this test for increased accuracy.

In my case, after my bite, I went to a walk-in clinic in Kittery, Maine. At the time, I knew very little about Lyme and I was told to wait 6 weeks and come back for testing then. That was a death sentence. Had the nurse known enough to give me antibiotics that day, based on symptoms, even without the tick in hand or a bulls-eye rash, it would have saved my life. At the time, my partner of 8 years and I were just starting to try for a baby. Had I been given antibiotics that day instead of being sent away to get sick, there is a good chance I would be a mother right now. Five years later I have to accept that I am too sick to carry a child, and I have spent over $60,000 out of pocket to stay well. I lost everything that day to a casual recommendation that easily could have been avoided.

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[6] https://www.lymedisease.org/greenberg-lyme-testing-problems/

[7] Lyme ImmunoBlot receives FDA clearance | IGeneX

Doctors face a lot of red tape, and in some cases, there is pressure to conform to a given set of standards. There are positives and negatives to this. We all know that sometimes, in this country, healthcare guidelines are sometimes affected by financial interests, and Lyme disease, if properly diagnosed, has the potential to be costly to insurance companies and states that depend on tourism. There has been an incentive to keep the reported numbers low. But, it is time to put all of that behind us. We can no longer afford to play that game. This has become too serious. And nobody should die, especially children, because of someone else's agenda.

Maine is the "Dirigo" State: Latin for "I direct" or "I lead." We know that every morning, in the continental US, Maine is the first place to see the sunrise. Tick borne illness is being called a silent epidemic, not because the numbers of afflicted are small, but because those suffering are typically silent, too sick to leave their house, sometimes their bed. This is happening to the whole nation, but we have a chance, with Bill LD1688, to once again lead the nation. We can help our medical professionals get the most up to date information perpetually. We can help them save lives and pull people out of years of suffering from chronic illness. In the past, medicine has focused on curing acute illness and managing symptoms of chronic illness. But the next generation is going to figure out how to not just manage, but to actually cure the causes of chronic illness, which very often have an infectious origin. We can be on the forefront of that movement. Dirigo.

Everybody in this hearing today knows somebody who will develop chronic Lyme symptoms in the next couple years. It will be a sibling, a parent, a child, or even themselves. They don't know it yet, but it will completely turn their life upside down and from that point forward, all memories will be divided between "before sick" and "after sick". We live in one of the most beautiful places in the world, but it is no longer safe for our children to hike in the woods or roll down a grassy hill. Childhood here has changed. Adulthood here has changed. A simple picnic in a field can leave you maimed for life. Having a dog is more dangerous than playing Russian roulette. We can address this. We can change this. And Bill LD1688 will go a long way towards helping our doctors, nurses and physician assistants contribute to the right side of history when it comes to recognizing and appropriately treating these horrific diseases afflicting our Maine communities.