



State of Connecticut
HOUSE OF REPRESENTATIVES
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Thank you Chairwoman Sayers, Chairwoman Handley, Ranking Members, and members of the Committee for the opportunity to testify today concerning **HB 5747**, a bill to require our state's laboratories to report incidents of Lyme disease infection. I will also be saying a few words about **HB6701**, a companion bill to establish a statewide Lyme Disease Task Force, which is not before the committee today.

I am a survivor. When you hear someone say this, you expect to see Lance Armstrong or Magic Johnson; you expect a public awareness campaign replete with meaningful information and statistics; and you expect leaders in government and the medical community to offer their strong support. But if you suffer from Lyme disease, you don't expect these things. I was lucky; I had a relatively mild case of Lyme that we caught in time. But today you will hear from friends and neighbors that did not have access to timely and effective diagnosis, and who didn't catch it early. You will hear from mothers whose whole families have contracted chronic Lyme, and who suffer alongside their children with chronic physical pain and debilitating psychological disorders. These courageous families are here to tell you what certain people in our government and the medical community do not understand – that Lyme is a chronic, debilitating and potentially life threatening disease that punishes a greater percentage of Connecticut residents than any other state in the Union.

Some of these families here today are proof of the scariest fact of all – that children under nine are most at risk of this debilitating disease. They know Lyme is more than a disease or condition. It is a menace, a dangerous threat we face every time we go outside to do the things we take for granted, like tending to our gardens, lying in grass, or playing with our kids in the backyard. Since we discovered the disease here in Connecticut more than 30 years ago, Connecticut has led the nation in the rate of infection, and we have every reason to believe that is still the case. A Connecticut town gave the disease its name. Lyme is in fact the most pervasive vector-borne infectious disease (meaning it is carried by animal or insect) in the United States. In short, we discovered it. We named it. We are most affected by it. And that's why we must lead the fight against it.

But Connecticut is not leading the fight. In some ways, Connecticut is hardly fighting at all. Because our Department of Health discontinued mandatory lab reporting of Lyme 4 years ago, we don't really know how many of our friends and neighbors have contracted Lyme, we don't know where families face the greatest risk of Lyme, and we can't tell the federal government, private grant sponsors, and public health advocates how much help we need. The Department of Health effectively chose to ignore approximately 80% of reported cases (the rest are reported by doctors, by whom compliance appears to be low). In 2002, Connecticut's labs and doctors reported 4,631 cases of Lyme. After the Department of Health cancelled mandatory lab reporting, only 1,810 cases were reported in 2005. In my hometown of Stamford, we reported 89 cases in 2002, but after lab reporting stopped, we reported only 18 in 2003. (You may hear that the Department of Health may reinstate electronic lab reporting, but the number of labs equipped to report electronically appears to be quite low). Even worse, experts from the Department of Health (Dr. Matthew Carter) and the Centers for Disease Control estimate that the actual reported cases comprise only 10-20% of the actual cases of Lyme disease. With our limited information, what we do know is that Lyme cases increased 34% statewide from 2004 - 2005, and tick infectivity rates are running 30% on state average. But to be otherwise willfully blind to the true extent of this menace is inexcusable. For the families here today, it is close to unforgivable. I urge you to pass **HB 5747** to restore mandatory lab reporting in Connecticut.

Mandatory lab reporting is just the start. Today, a controversy has erupted in the medical community over the diagnosis and treatment of Lyme. The Infectious Disease Society of America (ISDA) has promulgated guidelines that effectively deny the existence of chronic Lyme disease. This outrageous decision doesn't just offend or insult the families here today - it jeopardizes their health, and it risks the well-being of the children and families of this state. The Attorney General is investigating the ISDA. We must do our part and pass **HB 6701** to create a statewide task force charged with developing a real and immediate strategy to fight Lyme that is built on prevention, timely diagnosis and effective treatment

I want to thank State Representative Jason Bartlett for his leadership and for the opportunity to introduce this important legislation with him. Most importantly, I want to thank the courageous children and families who are here today, who courageously fight the debilitating effects of Lyme, and who patiently wait for us to take action to protect them.

Thank you.