

Public Health Committee

House Bill #6200

AN ACT CONCERNING THE USE OF LONG TERM ANTIBIOTICS FOR THE TREATMENT OF LYME DISEASE

My name is Karen Gaudian; I am co-chair of the Ridgefield Lyme Disease task Force and I also represent the town of Ridgefield on the Housatonic Valley Council of Elected Officials' Lyme Disease Task Force.

My family has been dealing with Lyme disease for almost 9 years. I would like to give a brief over view of my daughter's life since she was infected in the spring of 2000.

I thought we were lucky, our pediatrician recognized her symptoms and treated her for Lyme disease without a positive blood test; I thought we were done. She relapsed shortly after finishing treatment. In the fall she developed a positive test and went back on oral antibiotics but kept getting worse. She missed more and more school until her physician felt she needed to be put on homebound status; we were horrified. After fighting with our insurance company for 6 months she was put on IV; but the damage was already done. She was homebound unable to function, unable to read, with short term memory loss, cognitive problems and a constant headache. With 6 weeks of IV treatment we thought she would be cured, get back to school and her friends and move on with her life; but after treatment was stopped she relapsed again. Unable to get more treatment with IV she was placed on oral antibiotics; slowly she improved and went back to school part time. We could see the light back in her eyes, but again she was taken off antibiotics and again relapsed. This cycle of partial treatment and relapse has gone on for almost 9 years.

Each time her treatment is stopped her symptoms come back with a vengeance. She is currently unable to read, do schoolwork, see her friends and has to travel hours out of state to see physicians willing to help her. If treatment was continued until symptoms resolved the chance of relapse would be greatly diminished.

Over the years the CT Department of Public Health has received millions in funding for prevention and research for Lyme disease. This money has gone to only three health districts in CT to study and develop prevention programs. In spite of this money, and the fact that most residents surveyed by state officials report they are using preventative measures, each day 83 more people in CT become infected with Lyme and other tick-borne diseases. Prevention alone has not been able to stop this exploding epidemic and the numbers continue to rise at alarming rates.

In the wake of the Department of Public Health's failed prevention approach, we must turn to physicians across the state to properly address this dire situation. Health care professionals must be given the ability to diagnose Lyme disease clinically. There are no "Gold Standard" tests available for Lyme disease and available tests miss 50% or more of those infected. Physicians must be allowed to treat until symptoms resolve or go into remission, and retreat when or if necessary, using all treatment options available as we would in the event a cancer were not eliminated or returned. Citizens can no longer afford to be forced to follow a totally unsuccessful 'cost effective' limiting treatment protocol which has allowed up to 20% or more of those exposed to Lyme to become chronically ill or disabled due to lack of adequate treatment.

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