

February 4, 2009
Committee on Public Health
Connecticut General Assembly
Legislative Office Building, Room 4005
Hartford, CT 06106-1591

HB 6200

Dear Committee Members,

There are some patients who would like to write to you today to ask you to please pass HB 6200, *An Act Concerning the Long-term use of Antibiotic Treatment of Lyme Disease.*

They would also ask that you not only pass HB 6200, but that you continue to do all you can to help the patients that are dealing with this exploding epidemic that is sweeping the country. Rather than repeat what others who have written to you would say, and loading you down with the science (and there is a load of it) I would like to tell you about the letters you won't be getting and about the people who won't be writing them. There are many, but I'll only mention a few right now.

Kandy, who you would think had to be Meg Ryan's sister as beautiful as she is, would be one of those hoping to get her message across to you today, and undoubtedly she would ask- in that sweet southern drawl of hers- that you help us with our fight for proper treatment. Even though she spent more than eight of her Lyme years in a wheel chair, too weak to even pick up her young child to hug him, she would always say to me, "Oh shot! You're worse off than me, ya know." But I don't think so.

Then there is Mickey, a late night partying kind of fellow, not real popular with the ladies, but a gentleman by all means. If he were writing tonight, he would describe for you the huge purple-red rash he got that nearly covered his entire lower leg after the tick bit him. He would also let you know that the cancer he had was much easier to handle than the Lyme disease. At least with the cancer he was able to get proper treatment, insurance coverage and doctors who weren't afraid to treat him.

Frank, Terri, John and Arlene would warn you that Lyme disease can become a disabling chronic disease and that the IDSA is wrong when they say there is no such thing as "chronic Lyme". And Opal would tell you how many hundreds of thousands of dollars this disease cost her family over the years because she couldn't get help. And trust me, I know her, she would go on and on about how many doctors she had to see before she was diagnosed and no doubt she would also mention her 14 hospital stays in one year.

Jean would grumpily tell you, if you could even get her to talk, that she suffered multiple skin conditions, joint pain and depression. She would say she was eventually committed to a psychiatric facility because no one thought to check for Lyme disease until it was too late and her brain was nearly destroyed.

Dorothy would quietly mention, as if it were a secret, that she thought the tick that bit her was simply a mole that eventually fell off and left a spot of blood where it had been. She was getting elderly when she got Lyme and was not able to see too well. Of course, her aches and pains were blamed on old age, at first.

Dixie, a nurse and mother of three, would explain to you how it wasn't really the flu or a virus like she was repeatedly told, that had rapidly progressed into what they first called Parkinson's, then MS, then dementia, then Alzheimer's and then fibromyalgia along with depression. It was actually Lyme and Babesiosis that caused her to become bed bound at age 45.

And my friend John, we all call him Smiley, well, he would tell you his joint pain from Lyme was so bad he could no longer work on the water like he had done for years, like his father had done and his grandfather before him. The headaches he described were wicked. He said it was like having darts shoved in his head, along with a terrible hangover. He developed Bell's palsy and walked with a bad limp.

Mary Pat would be really upset if I wasn't jumping up and down right about now doing all I could to make you pay close attention to the Lyme situation and this vital bill. She worked for years as a nurse and became a dedicated volunteer Lyme advocate. And Rose, oh if she only knew Mary Pat and the other volunteers were working on this, she would be right beside them offering her support.

Vincent and his wife, yes, we all know they would be writing to you too asking for help with this bill. Vincent became so sick he wasn't able to work as an EMT and fire fighter any longer. He steadily worsened and became disabled from what they at first called "ALS". Years later they learned it was really Lyme disease and coinfections. He lost everything due to his illness, including his home.

Debbie, my dear friend Debbie. She is a spunky one who would be saying, "GO CT GO!" And she would be rallying for our cause, as sure as the sun comes up in the morning.

But I really want to tell you about my friend Billy. He also was diagnosed as having ALS- at age 30. And you are right. It wasn't really ALS, it was Lyme and tick borne coinfections. He was a landscaper in a highly endemic area and had many tick bites over the years due to his occupational exposure. Even after having many positive tests he was unable to be treated by his doctors. After all, admitting he had Lyme would have also set up the doctors who misdiagnosed him for a raging legal battle. Billy was finally able to find a doctor who would treat him for his infections and he started making notable improvements.

But Billy's doctor came under fire by the medical boards one day and even though Billy went to a legislative hearing to try to get a bill passed that would protect his doctor, it was all for naught. Billy, who had to have his brother read his testimony because he'd lost the ability to speak, was very brave to come before those so powerful in his one squeaky wheel, wheel chair. It was a shame the legislators let him and so many others down. They chose to listen to the wrong people, the Infectious Disease Society of America.

Had the legislators listened to their pleas and the bill had passed, perhaps Billy wouldn't have died while waiting for them to help? Maybe Kandy wouldn't have died from Lyme also, leaving her young son and husband behind? With most of her body paralyzed or in incredible pain, she died of respiratory failure.

There were more who waited and even begged for a helping hand, one that never reached out to them. Mickey passed away, as did Frank, Terri, John and Arlene. Before Opal died she spent more time in the hospital than the people who worked there, and Jean, well Jean lived in the nursing home once she retired from the military. She died lonely and miserable from untreated tick borne infections. Dorothy left behind many family members and friends who loved her dearly.

Dixie's family is still in shock since her death, from what started out to be a misdiagnosed "virus" that was suppose to be "no big deal", which progressed quickly into some of the worst conditions we know of today, all caused by Lyme. John's family and his many friends miss seeing him every day down at the docks. And many in the Lyme community remember Mary Pat and Rose and the work they did to help other patients before they passed away. Vincent's wife stayed by his side till the end, a devoted wife indeed.

And Debbie. Her doctor was sanctioned by the medical boards and she wasn't able to be treated. She relapsed and got worse each day until she was finally able to get some help. But it was too little, too late. She died the day before she was to go see her son graduate from college.

These dear people weren't the only ones who died while waiting for help. There are more than 600 others we know of who have lost their battles with tick borne diseases. And while we all still wait for help from those in power, like yourselves, a Lyme memorial site has been created to honor those who have passed.

If you care to visit the site, please do. I'm sure once you see our friends and families names, you will hear their pleas. My bet is they would like you to get this bill passed and stop the madness, so others will live.

Lyme Disease Memorial Park Project www.LymeMemorial.org

Thank you for taking time to listen to us, to all of us. The facts and the science are there to back your decision to pass this bill, so may your heart be your guide in this matter of life or death.

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