

SUPPORT FOR HB 6200 - Testimony

My daughter and I have both had our health severely impacted by Lyme disease and coinfections. In her senior year of high school she was diagnosed with mononucleosis and was anticipating a total recovery when she left for her freshman year of college. My daughter's Lyme disease diagnosis came in 1994 after she had to leave college in Ohio and return home. After two weeks of antibiotic treatment I was told she was well and any other issues were unrelated. She was not well or even functioning. I took her to an infectious disease specialist, who after listening to my pleas for help, finally agreed to allow her 28 days of IV antibiotics. He told me that was all that was needed. Her improvement of symptoms was slight during that month and because I couldn't get medical coverage for continued treatment I was out of pocket \$17,000. I had no choice I could see no future for my daughter without continued treatment. Even with several months of IV antibiotics and some improvement, as soon as she came off IV antibiotics, she would relapse. She couldn't take oral antibiotics because of severe gastrointestinal problems. In spite of everything my daughter, Margo, continued to go to college. She struggled, but it was all she had to relate to feel connected to life. Everything took a long time. While the other students partied, she rested and worked on her school work while living in an isolated existence at home. In 1998 Margo developed a movement/seizure disorder that left her incapacitated for 8 months. Had it not been for her Lyme doctors, there would have been little support. IV treatment was reinitiated thanks to an infectious disease physician who wasn't afraid to take a risk by ordering 11 months of antibiotic treatment. This probably happened thanks to the 1999 initiative where an infectious disease physician could order an extended amount of IV antibiotics and have it approved by the insurance company. I was proud that my daughter and I both had spoken at that Hartford Initiative Hearing in 1999. It was a determining factor in her future that this bill had been passed. My daughter's diagnosis has turned me into a Lyme advocate and I have worked in three Lyme disease practices. Every day I hear stories from patients from all over this country and yes, some patients even come from Europe. They want to know if there are any other Lyme literature physicians they can see that are near to them. Most often I have to explain that few physicians are comfortable taking the risks to be a Lyme physician because of the strict guidelines imposed upon physicians for making the diagnosis and treating Lyme disease. If Lyme patients are to be served well they need more physicians. Physicians who don't need to feel that their licenses are at risk for using their clinical knowledge to decide how to treat their patients. Please do anything you can to insure the rights of patients to decide with their physicians how they want to be treated. It is the right thing to do! On a happy note---Life will always be an adventure for Margo as far as her health is concerned. I never thought she would be where she is today and I am so grateful. I accept that we must live in the moment and be joyous that at 32 years old she has her Master's degree in counseling and is employed full time working as a therapist treating people with addictions. Without access to treatment this could have never happened. I got lucky, but you shouldn't need to get lucky to find medical care!

Bonnie Friedman, 54 Ceil Road, Trumbull, CT06611 Margo Friedman, 33 Teresa Place, Bridgeport, CT 06606