

Written Testimony of Heidi Maynard

03-01-2011

Public Health Committee

Testimony in support of HB6481, An Act Concerning the Establishment of a Lupus Education and Awareness Plan

Senator Stillman, Representative Ritter and members of the Public Health Committee. I am submitting the following written testimony in support of House Bill #6481.

I am 26 years old, and I was diagnosed with Lupus in 2004, my freshman year in college. I have lived in Connecticut my whole life, and I have seen more doctors than a typical family would see in their lifetime. My diagnosis, like many others was very complicated. I have had numerous health problems since I was a child and no one ever put the pieces together. I was officially diagnosed by a team of specialists at Yale New Haven Hospital. A spinal tap was done because I had lost all sensation in the lower half of my body. I had been tested for MS multiple times which is extremely scary to even think about. My family and I went through a very long and stressful time while they tried to diagnose me. No one in my family has ever had an auto immune illness, and my primary care doctor never even considered it. I had to withdraw from college as the stress was making my disease worse and the doctors didn't want anymore stress on my body. This was all very difficult to take in at 20 years old. My whole life was about to change and no one had any idea.

After I was officially diagnosed I started seeing a group of rheumatologists and other specialists to get me stabilized which took about 5 years. I have been taking handfuls of medication forever. I have finally gone into remission, and I am now 3 months pregnant which has brought up even more concerns for my health. I have been seeing many specialists but there are a lot of unanswered questions because the doctors just don't know the answers.

By passing this bill to put awareness and education out there would make a huge difference. I wish more doctors knew about Lupus, as it may not have taken so long for them to get me on the correct medications and stabilized. I could have completed college and been a normal 20 year old. I spent 5 years in a chronic state of pain and fatigue because the doctors just didn't know what was going on. This disease is just starting to finally get the much needed attention it deserves.

Thank you again for introducing this important legislation. I believe it will have a positive impact on the lives of patients living with lupus in Connecticut.

Heidi Maynard

Wethersfield, CT