

Written Testimony of  
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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 here today in support of Bill #6481, and in hopes of increasing Lupus awareness and education in the state of CT. I am a survivor of Lupus. As you may or may not be aware, Lupus is an extremely debilitating disease as debilitating as Lyme Disease if not worse. It is an autoimmune disease that causes the body to attack itself and attack the body's most vital organs including the heart, kidneys, lungs and liver. I would like to share my personal story with you. I was diagnosed in 2004 at the age of 30 during a routine doctor's appt. with my PCP in Manhattan, and had a positive ANA test. At that time I was immediately referred to a Lupus Specialist/Rheumatoid Arthritis Specialist Doctor Robert Fafalak of Manhattan. I am one of the lucky ones who was diagnosed immediately, treated aggressively, cured within a year, and fortunately it has not recurred. So often though, that is not the case. I am one of the 2% in the country where it has not recurred. My Physician Dr. Fafalak treated my Lupus very aggressively for a period of 1 year with the drug methotrexate, which is used most often to treat cancer. During that time because I was ill from both the medication and the illness itself, I was unable to work and was bedridden for an entire year. As a result of the Lupus I had many devastating life altering symptoms including losing 75% of my hair, gained 60 lbs which was caused by the side effects of the medication, the disease itself, and of course inactivity. Many of my other symptoms included: mini strokes, numbness in my hands and arms, overall weakness and complete exhaustion, dizziness, asthma, high blood pressure and Sjogren's Syndrome. To this day I still suffer from Sjogren's Syndrome and have severe sinusitis as a result, and every 2 months to due to dry eye I am required to have tear duct punctal insertion at my Optometrist office which costs 500.00 per visit. I am also constantly battling fatigue and have to devote 8 solid hours a night to sleep in order to avoid exhaustion and function properly throughout the day. Though I am healthy and working full time, I am still affected by the residual effects of Lupus.

Because so many women and men throughout the country, 1.5 million in the United States, are diagnosed with this debilitating disease I am here today asking you to support this bill in order to increase LUPUS advocacy, awareness, support, and research funding in the state of CT. I believe that with increased funding in my lifetime we will be able to find a cure. And with increased awareness and education, patients will be diagnosed in a quicker time frame, treated properly with the correct and safest medications available, and will be able to be treated by Doctors who are knowledgeable about Lupus and who

specialize in the treatment of Lupus. In addition, increased awareness and education will then lead to health insurance coverage for **all** those who suffer from Lupus.

At this time if I may, I would like to touch on health insurance briefly, because it is such an issue for myself and others in CT who suffer from Lupus currently, or who have been diagnosed previously. In 2010 I was denied health insurance in the state of CT by United Health Care through the broker Golden Rule, and was blatantly told by Golden Rule that the reason I was being denied coverage was because I “was diagnosed with the Lupus in the past.” After hearing this, I immediately explained to Golden Rule that I have not had Lupus for 6 years and it has never recurred. I also indicated that my Physicians in NY had submitted and faxed signed letters stating that I have not had lupus for 6 years. I proceeded to question Golden Rule asking “how much time has to pass before United through Golden Rule will cover someone who has had Lupus without a recurrence of the illness?” I was immediately told by Golden Rule that they “do not insure anyone who has been diagnosed with Lupus even if 20 years, 25 years or 5 years has gone by without a recurrence, anyone who has had Lupus in the past is outright denied.” I currently have individual health insurance however, because I have had Lupus I can only qualify for high risk health insurance in the state of CT, through Health Reinsurance Association of CT. When applying for individual health insurance, I am immediately put into a “high risk” category because of my past Lupus. My health insurance is 900.00 per month which is exorbitant to say the least, and it is twice the amount per month of what I would have paid through Golden Rule but because I am put into a high risk category in the state of CT, the least expensive individual health insurance I can obtain is 900.00 per month. In addition if my Lupus ever recurs, my health insurance company may drop me immediately and they do not cover Lupus medication as stated in my contract. This is a scary fact and the scary reality that many Lupus patients or past sufferers of Lupus in the state of CT face on a daily basis. And those who suffer from Lupus may not even be able to obtain insurance or keep health insurance in order to receive the medical care for their Lupus they deserve and require. What is also worth mentioning is that Lyme Disease which is also equally debilitating and devastating is covered by United Health Care through Golden Rule, is not considered high risk by United Health Care in general, and all medication including home IV therapy for Lyme Disease which is extremely costly is fully covered by United Health. Why is it that Lyme Disease is respected by these insurance companies and taken seriously, yet Lupus is not? Why is Lupus not given the same respect?

I am asking today that the lawmakers and legislation of CT realize how devastating and debilitating Lupus is, and as a result facilitate this bill. I truly believe that this legislation is a positive beginning, and bring hopes of Lupus finally receiving the respect and recognition it deserves, and the education and funding it demands. With this legislation also brings great hope to the Lupus sufferers of CT that one day soon, a cure will be attained.

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 CT.

