

Written Testimony of  
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3/2/2011  
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.

My name is Anita Kuan. I have lupus.

Growing up, I had “a bad case of the flu” every year. One year, I had one of the worst “flu” cases ever – complete with vomiting, 104°F fever, swollen joints, mouth sores, bleeding gums, fatigue ... the works. I was unable to eat and could not keep liquids down. I was dehydrated and had lost 40 pounds out of my then 125 pound frame (~1/3 of my body weight). After months of tests and trips to the doctors, still no one could explain what was happening to me. I was rapidly going downhill. I no longer noticed, or cared, what happened around me, or to me. Meanwhile, my mother kept asking questions, talking to friends, colleagues and doctors, and reading, always reading and trying to educate herself about childhood diseases, joint pain, etc. Her inquiries eventually brought her to a rheumatologist, Mitchell Forman, D.O. Dr. Forman took one look at me with my butterfly rash, fever, joint pain, and mouth sores and said simply, “lupus.” Blood tests confirmed the diagnosis.

I had **classic** symptoms of lupus. A textbook case. Why had no one thought of lupus? If House Bill #6481 existed then, my doctors may have thought of lupus. But, it wasn't and they didn't. Yet, I was lucky. My mother was a scientist – she was an expert at asking questions and extremely persistent. She educated herself. She thought to get a rheumatologist's opinion. But, not everyone has a scientist as a parent.

If this bill was already in place, my doctors would have known about lupus. They might have diagnosed me. The disease could have been caught earlier, before it progressed so far. We could have tried less aggressive treatments. Perhaps high dose steroids would not have been necessary. I would not have the beginnings of cataracts in my eyes now (a side effect of steroids). I would not have missed so much of high school, of life. The time I did spend in the classroom, and outside the walls of my bedroom, may have been easier if people knew something of lupus. I was tired all the time. My face was a balloon and I had drastically gained weight (the result of high steroid doses). I was self-conscious and people can be cruel without realizing how much pain they are causing.

Fast forward 26 years. New decade. In fact, **a new century**. But, the story is still the same. How can this be? Today, patients can still go years without a diagnosis, all the while suffering needlessly. Not to mention the days of missed work, lost jobs, lost relationships, missed opportunities, all the while medical bills piling up. Why? Lupus is not a new disease. The systemic form of lupus (SLE) was described in the year 1872. The treatment of systemic lupus was revolutionized in the early 1950's by the

discovery of the efficacy of cortisone (steroids). But, here we are in 2011 and cases of lupus can still take months and even years before being properly diagnosed.

My grandmother always told me, study hard. Learn things. What you learn is yours. It's in your head and no one can take that away from you. Her wisdom would seem to apply here, too. Education and awareness – it's the starting point, and cornerstone, for so much in life. If my doctors were more informed about lupus, they would have realized I had lupus.

Having lupus has shaped my life. It also fueled an interest in autoimmunity. How does the immune system work? *How, where, and when* does *what* go wrong that makes the immune system attack self? I pursued my studies in immunology, received my doctorate degree and took a position at the University of Pennsylvania. I saw how public awareness can affect lupus research, both in funding for basic research and in clinical trials, e.g., obtaining a good sample size for basic research studies or sufficient patient participation for clinical trials. The squeaky wheel does get the grease. People have heard of cancer. They've heard of AIDS. They've heard of heart disease. They donate to the Cancer Foundation or the American Heart Association (all worthy causes). But, lupus? Not so much. I found funding for research was competitive and grants for lupus research limited. And unfortunately, my health was declining. I did obtain research support from The Arthritis Foundation, but this career path seemed to be stressing my already precarious health. When my grant ended, I left the academic world and tried my hand at medical writing. I was hoping for flexibility in work, while staying involved in ongoing biomedical research. It seemed to be working. My most recent lupus flare has made it difficult. It has been a long, unpredictable flare. I have improved, but am still on many medications in the attempt to control my symptoms (debilitating fatigue, nausea, joint pain, headaches and migraines, low blood counts).

If this bill was already in place, perhaps more people would understand the debilitating effects of lupus and its flares and remissions. I am well-educated (PhD). I believe I have marketable skills (several years experience in academics and in the medical communications industry). Yet, I find it difficult to find work that can accommodate the unpredictability of lupus. If more people had heard of lupus, it might be easier to explain my fatigue. Lupus would generally be seen as a legitimate disorder, and not all in your head. I am now freelancing and working whenever I am able.

I often think about others with lupus, whether they have been diagnosed yet or not, and I think of the wasted talent and resources. Because of the lack of awareness, the lack of better treatments, and the late diagnoses, many people often do not reach their full potential. Instead they suffer, while their talents and skills go wasted or are not fully utilized. It is a deep loss.

On the bright side, it is inspiring to see that lupus research is progressing. I hope that lupus awareness and research continues to advance and that funding and support for this serious condition improves.

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.