

Written Testimony of
James and Lorraine Rogers
Public Hearing 3/02/2011
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.

We are submitting the following written testimony in support of House Bill #6481.

Because our daughter, Sharon, has lupus (Systemic Lupus Erythematosus), we know firsthand the need for increased education and awareness of lupus, both in the medical community and among the general public.

Lupus is a chronic, autoimmune disease that is debilitating and potentially fatal. Sadly, the complex, often seemingly unrelated symptoms, along with poor awareness of the disease among some doctors and the general public, make it difficult to diagnose. Sufferers often wait significant periods of time before seeking diagnosis or treatment. Yet, the faster they're diagnosed, the better chance they have at surviving and prospering. Our daughter is among the fortunate ones who was diagnosed relatively quickly. Yet we have heard of and met others who have been ill for literally years without being properly diagnosed and treated.

At the beginning of her illness, Sharon had debilitating headaches that lasted for 4-8 days without relenting, mental confusion while driving and taking public transportation, and intense fatigue that left her sleeping or resting up to 16 hours in a day. Her hands were often so numb that she had difficulty using her computer, which is how she earns a living. She had infections in her nose and ears, and severe joint pain that made it difficult, for example, to pour juice from a half-gallon container.

Yet, since she had recently moved back to the US after several years of working abroad and was unaware of lupus and its symptoms, she initially believed that she simply had a case of bad skin, a persistent cold, and stress-related pain and fatigue. She waited 6 weeks to seek a doctor, until even using the toilet became difficult.

After seeing several doctors for specific symptoms, she found a general practitioner who saw that the problems might be related and systemic. He referred her to a neurologist and a rheumatologist, as well as ordering a

range of blood tests. She was extremely fortunate that several of her specialists shared information and continued seeking a systemic explanation for her symptoms. Sharon was also fortunate that her doctors were persistent. Although initial blood work failed to show the markers of lupus, the dermatologist, whom she saw to treat a seemingly unrelated problem, the itchy, red bald spot on her head, suspected lupus was the cause and re-tested her. This time the blood work found definitive lupus indicators.

In all, 4 months passed from the time she first felt ill, to the time she began taking medication to quiet her out-of-control immune system and more than a year before the lupus flare died down and she entered a period of remission. Fortunately, treatment began before she had incurred permanent damage to her brain or kidneys or other organs. And with continued, life-long treatment, we all hope her lupus flares will be infrequent and not severe.

In addition to general lupus education and awareness, the medical community needs constantly updated knowledge of the drugs useful in treating lupus. Most of the drugs currently in use were originally developed to treat other diseases and have, over the years, been found to be also useful in dealing with lupus. It is vital that physicians be aware of the full range of drugs used, since many drugs have intolerable and deleterious side effects and some lose their effectiveness over time, so that trying alternative treatments is a common necessity.

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

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