

*Written Testimony of*

*Marilyn Sousa*

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*Public Health Committee*

*REVISED*

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

Good morning Senator Stillman, Representative Ritter and members of the Public Health Committee. Thank you for giving me the opportunity to testify in support of House Bill #6481. My name is Marilyn Sousa and I am a Lupus patient.

I was diagnosed in 1973 with a disease that I could not pronounce nor could I understand. , nor could I find anyone else who could pronounce it or understand it. My Doctor told me not to read anything about it, not to get pregnant and to stay out of the sun. But of course I did read about it and the only information I could find was that it was a fatal disease within five years. So he prescribed prednisone, and I learned that it caused many side effects, including bone loss, eye problems to name a few. I realized there was a great need for education and awareness about this disease so I founded the CT Lupus Chapter and organized support groups for Lupus awareness and education for the public. There is still much more to be done.

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