

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.

My name is Pauline Brignano. I am one of many people in  
Connecticut who suffer from lupus.

I am a volunteer for the Lupus Foundation of America (LFA),  
CT Chapter

My history with lupus goes back to 1970's; however, after  
seeing and being treated by four other physicians, it was  
not until 1994 that I was referred to the University Of  
Connecticut Health Center Dept. of Rheumatology. I was  
presented with a severe rash, joint pain and debilitating  
fatigue. I could barely walk and my fear was that I would  
spend the rest of my life in a wheelchair. Fortunately, I  
have the ability to walk and be here to give testimony.

It was at that time that I realized how little, if  
anything, people knew about lupus so I became involved with

the Lupus Foundation to educate myself. As time went on as volunteer I participated in health fairs in various communities and was shocked to hear from people that had lupus, or had a relative, a friend or co-worker they knew who suffered or died with lupus and then asked the question, "What is lupus?" Imagine a mother, a sister or a brother with lupus and no one in the family knows anything about the disease or that they themselves unknowingly may have an increased risk of developing lupus. A majority of persons I spoke with were young people of color and had very little knowledge of lupus. This is disturbing, a fatal disease such as lupus strikes young African American woman between the ages of 15 and 45. What resources does a young family have when a mother is disabled with lupus? At present the chapter has two paid staff members and a handful of volunteers, reaching out to those in need of lupus information and education and we cover the entire State of Connecticut.

Bill 6481 The Lupus Education and Awareness Program (LEAP) will expand upon improving lupus awareness and education throughout our state, therefore, creating better recognition of lupus, earlier diagnosis and treatment which can reduce or prevent serious health complications. Families, Schools, physicians, employers and health care workers need to have a better understanding and awareness of lupus. Through the Department of Public Health and Partnership Advisory Panel, we will achieve our goal of greater education and awareness of lupus in the state of Connecticut.

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