



Written Testimony of  
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The Lupus Foundation of America, Connecticut Chapter  
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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 honorable members of the Public Health Committee The Lupus Foundation of America, Connecticut Chapter would first like to thank you for raising this important bill to help patients affected by this disease and improve the care they receive in Connecticut.

The Lupus Foundation of America, Connecticut Chapter (CTLFA) would like to express strong support of HB6481 and encourage its passage. The CTLFA is the foremost nonprofit health organization dedicated to finding the causes of and cure for lupus, and providing support, services, and hope to all people affected by lupus in the state. The Lupus Foundation of America and national network of chapters, branches, and support groups conduct programs of research, education, and advocacy to help all those impacted by lupus.

Lupus is a chronic autoimmune disease in which the immune system is out of balance, causing inflammation and tissue damage to virtually any organ in the body. People with lupus suffer from a total loss of control; many lose their jobs, their homes and their ability to care for their families. Thousands die each year from lupus in the U.S. Lupus can be unpredictable and potentially fatal, yet no satisfactory treatment or cure exists. Every half hour another person is diagnosed with lupus. An estimated 1.5 million Americans and over 17,000 people living in Connecticut have lupus. Despite these significant figures, for the majority of people living with lupus, they had to wait over 4 years and see three physicians before they were able to receive a proper diagnosis.

Ninety percent of the people who develop lupus are women. Young women ages 18 to 34 are least aware of lupus, yet they are the group that is most often affected. Uncontrolled or undiagnosed lupus during pregnancy may result in the death of the mother. This contributes to one-third of lupus-related deaths occur among individuals younger than age 45.

Lupus is also two to three times more common in women of color. 90 percent of all individuals diagnosed with lupus are women and People of Color, African-Americans, Hispanics/Latinos, Asians and Native Americans are two to three times more likely to develop lupus. As many as 1 in 250 African American women will develop lupus. African American women are impacted by lupus at an earlier age, experience greater disease severity, have the highest overall death rates among all people with lupus and are three times more likely to die from lupus than their Caucasian counterparts. Health effects of lupus include heart attacks, strokes, seizures, miscarriages, and organ failure.

There is an urgent need for an arsenal of new treatments as current therapies have side-effect profiles that often prove worse than the disease itself. The Lupus Foundation of America is committed to finding new treatments and a cure. We were excited to be able to work with Congress to secure funding for the U.S. Health and Human Services' Office on Women's Health (OWH) for the Ad Council Campaign, "Could I Have Lupus?" This national campaign funded at \$2.3 million has leveraged in another \$60 million in earned media. I do not tell you this fact because we have hope of getting a large appropriation, but to demonstrate the need and desire that is out there to know more about this devastating disease.

Currently, only one in five Americans is aware of lupus symptoms and it's health effects. Most people with lupus don't realize they have a potentially disabling and life-threatening disease because symptoms, such as fatigue, skin rashes, joint pain and hair loss mimic other conditions, appear differently in different people, and can increase or decrease in severity from day to day. There is no single test to diagnose lupus so it can take years to diagnose lupus. It is because of these factors that more than half of the people with lupus visited multiple doctors and suffered with the disease for years before being diagnosed.

### **The Lupus Education and Awareness Program (LEAP)**

This legislation would create an Interagency and Partnership Advisory Panel who will be responsible for evaluating the current systems in place to educate patients and providers about lupus and developing a comprehensive plan to improve lupus awareness and education in the state. The goal of the plan would be to identify and address the lack of information and coordination around lupus identification and treatment in three key areas.

#### **1. Public Education and Awareness-**

What is most troubling about the lack of public awareness of lupus is that early recognition, diagnosis, and proper medical care often can reduce or prevent serious health complications, such as heart disease, strokes, seizures, and kidney failure caused by lupus.

#### **2. Healthcare Practitioner Education-**

Lupus is difficult to diagnose because some early symptoms may be dismissed as nothing serious. Because the disease develops most often in young people, and disease activity

can come and go over time, it is not uncommon for individuals with lupus to suffer several years before doctors make an accurate diagnosis.

If left untreated, the health consequences of lupus can be devastating and potentially fatal. One in four people with lupus is permanently disabled and thousands of people die each year from lupus complications.

### **3. Coordination of Public Health Efforts Concerning Lupus-**

Current public health efforts surrounding lupus awareness and education have been disjointed, sporadic and not effective enough.

While most Americans are aware of the signs and health risks of breast cancer or heart disease, relatively few are aware of lupus which is another potentially fatal disease that disproportionately strikes young African American women between the ages of 15 and 45. Low awareness contributes to late diagnosis and treatment of this potentially fatal disease

There are many sources for educational materials, i.e. the Lupus Foundation of America, the Alliance for Lupus Research, the National Institutes of Health, the Centers for Disease Control and Prevention, the Social Security Administration, and the S.L.E. Lupus Foundation, concerning lupus identification and treatment that could be used part of an overall educational strategy.

As with any chronic disease early diagnosis and preventative treatments are vital in controlling what can be outrageous costs to the healthcare system. The average annual cost of medical treatment for a person with lupus is \$10,000 to \$30,000. This leads to annual costs totaling \$31.4 billion in direct and indirect costs in the U.S. and \$47,100,000 in total costs for Connecticut.

We urge the Public Health Committee and the Connecticut Legislature to join with Illinois (who has enacted this measure), Massachusetts, Rhode Island, and Washington (who are also in the early stages of consideration) and the lupus community here in Connecticut and across the United States to raise awareness and educate about lupus so that we may one day have better treatments that will eventually lead to a cure. By authorizing HB6481 you will be giving the 17,000 people in this state living with lupus a voice in becoming a partner in their fight.

Thank you again for your consideration of HB6481, we look forward to your support in fighting lupus.

Sincerely,

*Lisa Sartorius*

CEO/President

Lupus Foundation of America, CT Chapter