

# **TESTIMONY**

## **In Support of Raised Bill 6481 AAC The Establishment Of A Lupus Education And Awareness Plan**

**Public Health Committee  
Wednesday, March 3, 2011**

Dear Senator Gerratana, Representative Ritter, Senator Welch, Representative Perillo and members of the Public Health Committee:

I respectfully urge your support and favorable action on Raised House Bill No. 6481, AAC The Establishment Of A Lupus Education and Awareness Plan.

Currently I serve on the board of directors of the Lupus Research Institute, an organization founded by lupus patients and their families and dedicated to funding research to find better treatments and a cure for this dread disease. We are proud to join the Connecticut Chapter of the Lupus Foundation of America in an effort to promote education and awareness concerning lupus, and we would ask that in its final version this bill simply include the participation of both organizations.

In today's economic climate, we must collaborate between lupus organizations, between the state organizations and with federal initiatives in order to most effectively accomplish the goals set forth in HB6481.

The federal government's program, "Eliminating Health Disparities in Lupus Initiative" (EHDLI), funded through the Office of Minority Health is a national effort to train and educate healthcare professionals to diagnose this often unrecognized disease. Lupus is a significant national health issue that deserves a comprehensive and coordinated response by state and federal government with involvement of the health care provider, patient, and public health communities.

The goal is national but for them to succeed, we must do our part locally beginning with the passage of HB 6481. EHDLI serves as a growing and valuable resource for Connecticut to draw on in this public health initiative.

Connecticut has world-class healthcare professionals, thousands of lupus patients and some of the finest medical schools and researchers anywhere. I find it shocking that the average lupus patient waits 3 to 5 years in what we call the “agony years” before she is diagnosed and receiving any treatment or disease management. 90% of lupus patients are women between the ages of 15 and 45, and it disproportionately affects women of color. A health disparity that remains unexplained.

My younger sister was diagnosed at age 25 and lost a long and courageous battle with lupus just after her 50<sup>th</sup> birthday seven years ago. I know too well the challenges of a life with a chronic disease that is often not recognized or is misdiagnosed by physicians, and for which patients still await the first drug developed specifically for their treatment. Not one drug for lupus has been approved in over 50 years.

We must educate our healthcare providers so that they diagnose and therefore treat lupus patients. We must educate the citizens of Connecticut so that they recognize lupus symptoms and seek medical care. And we must support the scientific investigators as they work to unravel the mysteries of this little understood disease.

Your passage of HB 6481 and the ensuing education and awareness just might save the life of a young woman you know.

Thank you again for your time and consideration on this very important issue.

Hope Hetherington