

Written Testimony of  
Michael F. Ganino  
Treasurer of the Lupus Foundation of America, Connecticut Chapter  
March 2, 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. I am submitting the following written testimony in support of House Bill #6481 "AN ACT CONCERNING THE ESTABLISHMENT OF A LUPUS EDUCATION AND AWARENESS PLAN."*

In 2007, I joined the Lupus Foundation of America Connecticut Chapter's Board of Directors. As the volunteer Treasurer, every day I see how hard our organization works to provide resources such as support groups and educational materials to those with lupus, but as the son of someone who has lupus, I've seen firsthand, the personal toll this disease can take on a loved one.

After years of seemingly endless doctor visits, none of which produced any significant diagnosis or improvements, my mom, Patricia Ganino, was diagnosed with lupus in 1991. As she was soon to discover, there were no support groups, no lists of doctors to visit and seemingly no one else to understand what she was going through. It would take years for her to realize that there were thousands of others in just Connecticut that were living with the same condition that she was.

Even back then we knew the best way to educate people about lupus was to talk about it, so in 1992, my senior year at SCSU, I choose "Living with Lupus" as my Communications class project. As I spoke, I realized the majority of my peers had never heard of lupus, despite the fact that more people were afflicted with lupus than multiple sclerosis, muscular dystrophy and cystic fibrosis...combined. Lupus appeared to be a disease that no one talked about and even more people had never even heard of.

Since then, I've been introduced to hundreds of people living with lupus and those with loved ones or friends in similar circumstances. I've met those who have endured the effects of lupus for far longer than my mom has, and in some cases even more heartbreaking, young children with lupus. At every opportunity, I try to discuss lupus and how our organization can help those who suffer from it, even if it's only an opportunity for them to talk with another sufferer about shared experiences or how they cope with lupus.

It is for my mom and these individuals, especially the children, that I ask for your support of House Bill #6481. This bill, among other things will help develop and implement a comprehensive plan to improve education and awareness surrounding lupus for health care practitioners, public health personnel, patients and persons who may have lupus. I can only wonder how things would have been different for my mom had this bill been in place when she was diagnosed.

I'm sorry I could not offer my testimony in support of House Bill #6481 in person. Thank you again for introducing this important legislation. I'm confident that with your support, lupus will one day be a distant memory and with the high quality of home grown research facilities we have in our state, that this effort will begin in Connecticut and will have taken root in the passing of this bill.

Respectfully yours,  
Michael F. Ganino