

Written Testimony of  
Lori Carpenter  
3/2/11  
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 Lori Carpenter, my husband and I “were” the parents of a Lupus patient.

The summer of 1999 we brought our son for a routine physical for school. The pediatrician found irregularities in his blood tests which led to a CAT scan. Nothing was found in the scans so the pediatrician decided he was going to do periodic blood work as a follow up.

By the fall of 1999 more issues arose and he was hospitalized.

Looking back he wasn't a sick child but did develop colds and sinus infections quite often, could that have been a sign of things to come?

It took three weeks in the hospital for our eleven year old son to be diagnosed with Lupus (SLE) which involved several blood tests, scans and finally a kidney biopsy.

We thought great now we have a cause of the problem and the doctors will give us the answer. Unfortunately that wasn't the case. We were told not much is know about Lupus, it usually causes joint pain and is most common in African American women in their 20's. We looked online for any help we could find and it just wasn't out there. We went from kidney specialists to arthritis specialists even to pain management doctors with no direct answers or actually help.

At the time of his diagnosis (October 1999) we along with everyone we knew had no idea what Lupus was or how he ended up with it. At the time of his death at the age of 16 (September 24, 2004) still no one could give us the answer.

It was a long hard journey for Kyle. Everyone who loved him watched helplessly as he went from doctor to doctor all trying to figure out how and what to treat him with. There were many drugs and many side effects along with a surgery to place a catheter for peritoneal dialysis.

Kyle was dealing with many issues emotionally and physically. No eleven year old should have to go through this alone. The information available for him and for us, as parents was very limited.

With education, research and awareness of Lupus, we believe this could help the medical community; along with the general public have a better understanding on how to help other Lupus patients.

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

Email Public Hearing Testimony to:  
PHC.Testimony@cga.ct.gov

Mailing Address:

Public Health Committee  
Room 3000, Legislative Office Building  
Hartford, CT 06106  
Phone: 860-240-0560