

Written Testimony of
Mary Luciano
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Parent of affected Child with Lupus Nephritis
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 Mary Luciano. I am a parent and care giver of an amazing 17 girl afflicted by the horrible disease with no cure. I represent a family that is now reliving the same process that took place 40 years ago when my mother-in-law died from this same disease due to lack of knowlege and access to physicians that knew how treat this disease.

This bill is so important to pass. Every day I am explaining and sharing with people the devastation this disease has had on my daughter and family. In the three years since we have been LIVING with this disease. I have spoken to hundreds of people who are unaware of what this disease is, what is does and what isn't available for resources. I have educated the teachers who are responsible for my daughters education. I have spoken at lengths with physicians that are not hands on with this type of disease. There is still lots of education that needs to be done and provided to the employers for the parents/spouses who take care of our children/spouses and have to take FMLA, schools where are children try to be every day no matter how they are feeling. There is an urgent need to have every bit of information available to the public,support groups, physician offices to get current materials for their patients and families.

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.