

## Testimony in support of SB 200

### **An Act Expanding Health Insurance Coverage of Specialized Formula for Individuals with Eosinophilic Disorders**

#### **Insurance and Real Estate Committee**

**March 6, 2014**

Thank you for giving me the opportunity to testify in support of SB 200 to expand coverage of medical food. My name is Eileen Landry, I live in Fairfield, Connecticut and two of my children have Eosinophilic Esophagitis. My eldest, who will be 13 next week, was diagnosed 5 years ago and my 4 year old was diagnosed as an infant.

EE is a rare autoimmune disease that, when active, causes inflammation in the digestive tract due to the overproduction of eosinophils. Diagnosis can only be made with endoscopy and pathology biopsies. Diagnosis for the disease was an extremely lengthy process for my sons. With respect to my children, repeat endoscopies are performed to determine whether or not the disease is in remission. We have learned that treatment for the disease is even more of a process to manage and maintain. According to the American Academy of Allergy, Asthma & Immunology, "EE can cause food impaction, recurring abdominal pain, trouble swallowing and vomiting" [all with the consumption of solid foods and their proteins]. This is what our children live with on a daily basis. You and I take eating a mere snack for granted. Our children cannot live with that luxury. Every morsel of food that they consume can wreak havoc within their bodies.

My eldest son, Conor, is scarred – his esophagus is damaged. Every 3 months he undergoes procedures that determine his need for a feeding tube. Conor has participated in clinical trials, food trials, elimination diets and medications such as swallowed steroids. All these efforts in hopes of healing his damaged digestive tract. The stress of having a child with a chronic disease is remarkable enough; add to that the pressures of the financial burdens associated with the disease – a truly terrible combination. Fighting the disease is awful enough to witness-- our children are in chronic pain. Why do we have to bear the challenges and struggles of fighting for necessary insurance coverage as well? In just days, the formula that Conor consumes to supplement his diet will no longer be covered, as he will be turning 13. What are we to do then?

My four year old, Christopher, is also on prescription formula. Thankfully, he takes it orally; although his interest in doing so decreases on a daily basis and soon, we may have to face the hardships of tube feeding him as well. He currently has a restricted list of foods and is supplemented by an amino acid based formula prescribed by his gastroenterologist. When first diagnosed, we had to appeal our self-funded insurance company to cover the cost of his formula.

We have found that when purchasing his formula, there is a negotiated rate between our insurance company and our drug store provider. When our allocated usage has been consumed, we pay out of pocket for any additional formula consumed. Why is the

insurance company able to pay the drug store provider a negotiated rate while we are obligated to pay full retail price? Why can't my family receive the same discount?

Paying for the medical supplies and bills for 2 children with EE is a great financial burden. What is a parent to do if they don't have the financial means to feed their child what he/she needs?

Insurance companies should employ common sense -- a well nourished, developing child is less expensive to treat than treating the ongoing, complicated results of an improperly nourished, failure to thrive child. In simple terms, a child's need for nourishment continues through their developmental years.

Who is the making the decisions regarding the welfare of my child, the numbers on a financial statement or the doctors who are actually treating my children on a regular basis? Don't you think the treatment researched and approved by the medical profession is reason enough to support this bill?

One last question, if insurance companies validate funding coverage until the age of 12, do insurance companies actually believe that the disease disappears when a child wakes up on his 13<sup>th</sup> birthday?

Thank you for considering the change to this bill,  
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