

January 25, 2017

Dear House of Representatives Insurance Committee,

My name is Caden Jones. I am writing you today about House Bill 2103, which is about insurance companies paying for medical food.

I am 13 years old and have a disease called Eosinophilic Esophagitis or EoE for short. This makes me feel really bad some times. When it first started, I was having trouble eating and breathing. It felt like someone was choking me. When I tried to eat food, I could chew it up but sometimes my throat was so tight, I could not swallow. This was the worst time. I told people and doctors what was wrong but at first they did not seem worried. They only became worried when I lost over 15 pounds in about 6 weeks.

I had to see many doctors before they figured out that I had EoE. Once Dr. Hattar said I had it, she had me go off of wheat and milk, plus start some medicines. This still was not making me better so she said I had to go off more foods! Now, I could not have wheat, milk, soy, shellfish, fish, eggs, nuts or peanuts. All of my favorite foods were gone. Can you imagine no more pizza, hamburgers, ice cream, crackers, spaghetti, and the list goes on. This is when I started to drink some of the elemental formula a little. Eventually, beef and corn were added to this list.

After being off all of those foods and the medicines, I had another scope and now it was worse than before. They did not know what was causing it and they referred me to Children's Mercy in Kansas City to see a specialist.

More tests, and they still do not know what my EoE triggers are. Right now, we found a combination of medicines that seem to be working. After the scope, I will know if the medicines are working. If they are not, I may still have to go on the elemental formula and stop eating all foods. When you go on the formula, you eat nothing else. I don't want to have to do it but I know that I may have to someday to find out what is causing me to be sick.

EoE tough on me. I am the kid at school or a birthday party that has to eat different food.

I am the kid that carries a lunch bag of food into a sporting event and the movie theater.

I am the kid that gets teased for being different and not being able to eat REAL food.

I am the kid who sometimes does not have the energy to play.

I am the kid who cannot go to brick and mortar school because I can't make it through the day without getting sick or fatigued.

I am the kid who just wants to be normal and happy.

I am the kid who sees my parents struggle to take me to my appointments and figure out how all this will be paid for.

I am the kid who thinks they should not have to.

Please pass this bill so that my parents have one less thing they need to worry about.

Sincerely,

Caden Jones

A Kid Living with Eosinophilic Esophagitis