

January 25, 2017

Dear Kansas House of Representatives Insurance Committee:

I am writing you today regarding HB 2103, the Medical Nutrition Bill.

My son, Caden is a 13 year old, who suffers from a rare autoimmune disease called Eosinaphlic Disease or EGID. Specifically, he has Eosinaphlic Esophagitis (EOE) and eosinaphliic gastritis. For Caden this means constant struggles with food, food impactions and inability to swallow food and liquids.

Caden is normally a lively and energetic boy. He currently an 8th grader at Maize Virtual Prep school. Previously, he attended Winfield Public Schools, but due to frequent absences and illness due to his EoE, we chose virtual school for him for this year. This soccer playing, swimming and adventurous child had his life turned upside down 1.5 years ago.

The summer of 2015, he began having problems swallowing and breathing. After losing a significant amount of weight and several doctors later, he was diagnosed with EOE.

He is literally allergic to the proteins in food. The proteins in food cause a buildup of a type of white blood cell, called an eosinophil, in the digestive tract and blood in response to a food or foods he eats. Eosinophils are meant to attack parasites, but the body of a patient with EGIDs mistakes food for a parasite. As a result, the buildup of eosinophils causes numerous and very serious health problems, including failure to thrive, uncontrollable vomiting, severe stomach and throat pain, inability to sleep, joint pain, and long term damage, just to name a few. Many people with EGIDs can only eat 1 or 2 foods and some need a feeding tube to survive.

At this time, we do not know what is causing Caden's problems. He has been placed on an elimination diet of wheat, milk, soy, eggs, nuts/peanuts, shellfish/fish, beans, beef and corn. He continued to deteriorate on this diet. He has tried all the medications that are at times helpful for EoE, yet none of these medication are approved by the FDA for this use. The only treatment approved by the FDA is the elemental diet of Amino Acid based formula like Neocate or Elecare, which is our next step for him. These formulas are free from the proteins that cause the buildup of eosinophils.

This elemental formula may be his last resort for treatment and is the only FDA approved one. The problem is, that health insurance companies in Kansas are not required to help pay for this life saving food, so they do not. This could be the only medicine can treat my son's condition, and help find out what his actual food triggers are. Once on an elemental diet, foods are added back 1 or 2 at a time until a problematic food is found. This process can take a few months or years. Out of pocket, this formula could cost us \$1500 or more per month.

My husband and I are both work for the public school system. My husband teaches 5th grade in Cedar Vale and I am a "teacher" per my contact, but am the Physical Therapist for the Cowley County. Like most families, we do not have it within our budget to afford to pay for his formula.

We attempted to get my son on Medicaid but he did not qualify due to our income level. There were 3 options that we came with to be able to afford his treatment is: 1) Run up our credit card and possibly in the future declare bankruptcy, 2) One of us quit our jobs, which would put us within the financial range to qualify for Medicaid. This option would also require us to sell our home. And 3) Get a divorce to separate our assets to qualify for Medicaid.

No family should have to choose between feeding their child and their home, marriage or career. Medicaid, Medicare, Tricare and many other states have already passed bills similar to this one and are covering cover medical food. Private coverage is the only insurance that does not cover it at this time.

Please help us and other Kansas families like us by requiring private insurance companies do what is the right think for families and children.

Sincerely,

Andrea Jones