

January 24, 2017

Kansas Committee on Insurance

Re: HB2103

Dear Committee Members:

Thank you for taking the time to review the Bill HB2103 regarding Amino Acid Formula Nutrition insurance coverage for the people of Kansas. My name is Kellie Crnkovich and I live in Ellis, KS my son has Eosinophilic Gastrointestinal Disease. This bill is very important to our family and others in Kansas. I want to share our story and why this is so important.

My son Joey is 14 years old for the last several years he has struggled with severe abdominal pain at first the Dr.'s believed it was IBS so he started taking medication for that. He kept getting worse despite changing and adding new medications and losing weight. In 2015 he started 7th grade he also started football he was very excited for that as his grandfather is a HS football coach in California. He kept getting sick with stomach issues and losing weight he also had 3 anaphylactic issues that we could not determine cause of. Dr. added Ensure formula to help with his nutrition and referred to allergist which had a 6 month wait to get in. As we were waiting Joey kept getting sicker by this time basketball season had started and he was trying to get through that as well. During Winter Break he was sick the entire time we added pedialyte every day to help with electrolytes. School started and he broke his foot jumping rope we realize now that was due to vitamin deficiencies from malabsorption. Again, a few weeks later we were back in the ER this time CT scan was done. It showed colitis and ileitis, an enlarged spleen, and enlarged lymph nodes. He could barely get out of bed.

Off to Salina to see a GI they did a colonoscopy to check for Crohn's no Crohn's showed up. Next went to a different Pediatric GI in Wichita she did an Endoscopy and found Eosinophils in his esophagus with chronic esophagitis. More meds and referral to Eosinophilic specialist at Children's Mercy in Kansas City. During the wait for this appointment we saw allergist he tested allergic to all but 3 things environmentally and to the foods Dairy, wheat, rye, barley, corn, seafood, and shellfish. Here we had been giving him Ensure several times a day and he was allergic to it causing his body to attack his GI Tract. We had to keep him on it for a few months until after new scopes. In July we had Endoscopy and Colonoscopy at Children's Mercy. He had Eosinophilic disease in his Esophagus, Ileum, and Colon elimination diet started. He started Virtual School since he did not have the energy to attend Brick and Mortar School. We tried switching to a Soy based nutritional supplement and his stomach swelled up like he was 6 months pregnant so that was a fail. We then switched to the Amino Acid Formula Neocate E028 Splash. This Formula is designed for older children it is an 8oz "juice box" it costs \$132 for a box of 27 if ordering online from Amazon. Joey currently drinks 60 a month and takes 13 medications. We have now eliminated Dairy, soy, wheat, rye, barley, eggs, seafood, shellfish, potatoes, and corn from his diet with more expected in the future.

As with many of these children these children there is a real possibility of him needing a g-tube and going elemental Amino Acid based formula only until his damage has healed. This would put formula costs at \$2000 plus month. Joey is finally gaining weight and doing well in school thanks to the formula. These formulas keep our children nutritionally fed and are vital to their healing and heading towards remission.

Families can not afford these costs when Insurance does not cover them. Many states, Medicaid, Medicare, and Tricare have added Medical Nutrition Bills and it is helping these children. I implore you to allow Kansas to be the next state to add this Bill and give Kansas Children the Nutrition they need to grow, learn, and get back to leading the life of child. Thank you so much for your time, consideration, and anticipated support of HB2103. Please feel free to contact me with any questions or clarifications.

Warm Regards,

Kellie Crnkovich

Ellis, KS