

3/18/2014

Dear Pennsylvania House Children and Youth Committee Members:

We urge you to pass legislation to convert House Bills 49 and 1436 into law, which will require prescription drug benefits and health care policies to provide coverage and reimbursement for amino acid/elemental formulas ("medical food").

Amino acid/elemental formula is the most effective treatment proven by medical research for eosinophilic gastrointestinal disorders. This formula is highly expensive, and many insurance companies refuse to pay for it. Currently, in the state of Pennsylvania, insurance companies can, and have, denied claims for this formula for children despite medical specialists' appeals and documentation of medical necessity, leaving families at a loss to help their suffering children. We need your help. Insurance coverage of this medical food will have a direct and immediate impact on improving the quality of life of families living in the Commonwealth of Pennsylvania.

Our son, Ryan, is four years old and has a rare and chronic disease called Eosinophilic Esophagitis (also known as EoE). Because of this disorder, Ryan experiences chronic inflammation and damage of his gastrointestinal tract, ongoing pain, difficulty swallowing, vomiting, constipation, refusal of food, malnutrition, poor growth, sleeping difficulties, and a whole host of other symptoms. A piece of cake, a bowl of rice, an apple, even a single carrot stick can make kids like Ryan violently ill. If untreated, they can suffer life-threatening consequences, including impaction of the intestines and food impaction in the esophagus. Every other month, Ryan must endure an invasive endoscopy with biopsy under general anesthesia at the hospital to see if the limited food he is allowed to have is safe. He will be undergoing his eighth endoscopy at the end of the month, and there are only 11 foods he can eat safely right now. His primary caloric intake comes from a special hypo-allergenic, amino-acid based prescription formula (or "medical food") to make up for food he can not have.

Ryan's doctors have followed best practice protocols, including medication management and elimination diets, which were unsuccessful; he remains dependent on this elemental formula to meet his daily nutritional requirements. This formula has made a major difference in Ryan's life and has allowed for his body to begin to heal. Although his medical journey is far from over, we are happy to say he is now much more medically stable.

We were shocked when Highmark Blue Shield denied coverage for Ryan's prescription formula deeming the formula/medical food as "not medically necessary," especially given that our team of medical specialists, including a pediatric allergist, pediatric gastroenterologist, and dietitian did deem it medically necessary.

We, along with our son's doctors appealed to our insurance company numerous times, but Highmark continued to deny coverage utilizing numerous "excuses" for why they

would not cover this formula – at the time, Ryan’s sole source of nutrition. Because Ryan’s health could not wait for Highmark to fund this, we had to pay out of pocket for the formula. Formula costs about \$35 per can, and Ryan’s diet requires one can about every 1.5 to 2 days. Doctors estimate that he will need to be on this formula for at least three years. We simply could not afford the cost of Ryan’s formula without insurance coverage, and went into financial debt as a result, but we are willing to do whatever it takes to get him the care he needs. Life without food is extraordinarily difficult both for the child and his/her family. It has been challenging and heart-breaking watching Ryan’s struggles physically, socially, and emotionally in not being able to eat like a typical four year-old. Lack of insurance coverage placed an unnecessary additional stressor and financial burden on our family. Spending months chasing down our insurance company wasted many hours of attention that should have been focused on helping my son heal and grow.

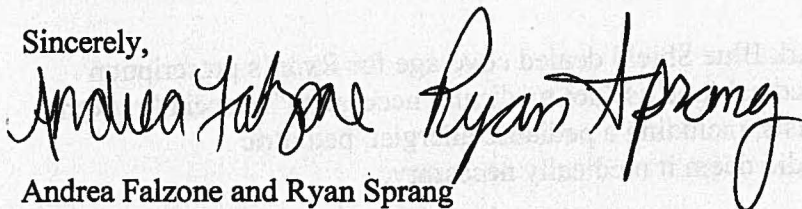
In May 2013, we sent a petition to our insurance company after our family had exhausted all other avenues, including doctors’ appeals, family appeals, appeals to my employer, and calls to various care managers. This time, Highmark paid attention as the petition earned 323 signatures in less than 24 hours and was quickly gaining momentum. After many months, they finally agreed to cover Ryan’s formula. We feel unbelievably fortunate to have a support network of family and friends that helped rally support and put pressure on our insurance company to “do the right thing.” However, our 2 year old son, Brayden, has recently also been diagnosed with this awful disorder, and we fear that we will have to battle with our insurance company once again to cover elemental formula if this treatment also becomes necessary for him.

Unfortunately, our story is not the only one of its kind. Many other families continue to struggle to fund their child’s medically necessary formula.

Many states mandate coverage of elemental formula so that insurance companies cannot do this to children; unfortunately, Pennsylvania is not one of these states. You, as a committee, have the power to change this and to ensure that children with such disorders get the care they need in the Commonwealth of Pennsylvania. *Insurance coverage will have a direct and immediate impact on improving the quality of life of families living in the Commonwealth of Pennsylvania.* **In our great country, no child should be denied the care he/she needs to survive.**

Please pass House Bills 49 and 1436. Thank you in advance for your time and for supporting families who suffer from these debilitating diseases.

Sincerely,

Handwritten signatures of Andrea Falzone and Ryan Sprang in black ink. The signature of Andrea Falzone is on the left, and the signature of Ryan Sprang is on the right, written in a cursive style.

Andrea Falzone and Ryan Sprang