

Suzanne Harris - Testimony

My name is Suzanne Harris. I live in West Chester, Pennsylvania, in the 156th District and I am the mother of Dean and Cole who are 11 and 10 years old.

I am here today because elemental formula must be covered by all insurance companies in Pennsylvania. Without this coverage, families struggle emotionally and financially because they can't afford to give their children the medicine they need. I don't want anyone to ever go through the experience I'll share with you today.

Dean and Cole were born with eosinophilic esophagitis -- a disease that is triggered by a type of food allergy.

I have seen my children suffer more than any parent should: hemorrhaging, vomiting, choking, frequent infections, bouts of respiratory distress and deemed failure to thrive. On the date of my 2nd wedding Anniversary, when Cole was just 8 weeks old, I was home alone with both of my babies. My already sick infant was on a feeding tube. He stopped breathing. Everything in his little body just stopped. I successfully performed CPR and called 911. I continued to live in fear.

For years, we lived, we slept, even celebrated holidays, in a children's hospital in Atlanta, Georgia. Our lives were filled with doctors, drugs and despair.

When my husband, Steve, and I finally learned that the boys had eosinophilic esophagitis, we moved to West Chester, Pennsylvania to be close to the Children's Hospital of Philadelphia and The Center for Pediatric Eosinophilic Disorders. We wanted to give Dean and Cole access to the best care for their disease.

And so began years of removing food from their diets followed by surgical procedures with biopsies every 8 weeks, all with general anesthesia. We said goodbye to nearly every food you can think of. Despite that, the biopsies kept coming back bad. Worse than that, our boys were still sick.

When our doctors said it was time to start elemental formula, Steve and I adamantly refused. I, like many people, did not see how I could suddenly remove all foods from their diets. Or how this could be our only option? But it was the only option. I also knew that most insurance companies denied coverage of this formula and, to be quite honest, I feared financial ruin. I hated that Steve and I had to even think about money. This was about saving Dean and Cole. This was our only option. But how could we provide for their other medical needs without financial stability?

No parent would elect to take food away from their children and replace it with formula unless it was the only hope. Being forced to make this decision is hard enough. Combining this with the stress of insurance appeals and mounting financial debt makes an already traumatic experience that much more unbearable.

Dean and Cole started elemental formula in November 2010 and they chose to drink it by mouth. For their first formula meal, I thought we could still sit around the family table at night like a normal family would at a mealtime. I prepared bowls of ice chips and set them at our four place settings along with Dean and Cole's boxes of formula. Our tears melted those ice chips faster than anyone could eat them. Steve and I cried watching our little boys, unsuccessfully, choke down the formula. Our boys cried at the taste. A taste they'd be forced to endure for as long as it took to work. After that night, Steve and I did not eat in front of our children. We ate at work or at home inside of a closet.

My fear came true. Our insurance company denied coverage. We incurred an incredible amount of debt. I spent countless hours and weeks on the phone with our insurance company fighting our case. Over time, I won. But we're only one family. What about the other families spending countless hours, often in vain, advocating for their children? These are hours that could be better spent volunteering in grade school classrooms or going on family bike rides.

Today, neither Dean nor Cole need elemental formula. They will likely never need it again. Dean needed formula for about 8 months. Cole needed it for about 14 months.

Elemental formula was the only reason our boys stabilized. Through elemental formula, their biopsies came back normal; their symptoms disappeared; they are back within the average range on growth charts. Their deprived bodies were finally able to receive the nutrition they desperately needed. This formula is the only choice many families have.

As a parent of chronically ill children, I still have many fears. Today, I am asking for your help that financial ruin not be one of them. Today, I am asking that you please support House Bills 49 & 1436.