

An Act Expanding Health Insurance Coverage of Specialized Formula for Children with Eosinophilic Disorders

Insurance and Real Estate Committee

February 19, 2013

Thank you for the opportunity to testify in support of House Bill 5432 to expand coverage of medical food.

My two year old daughter loves the color purple, dancing, and playing like “doggies” with her big sister. When she was born everything seemed perfect. At 4.5 months old, we got the cameras ready and excitedly prepared her first bowl of rice cereal. She took a few bites each day, but things just didn’t seem right. Her sleep became more disrupted and she seemed irritable and uncomfortable. We decided to hold off. A few weeks later we offered the rice cereal at dinner time, bathed her, and tucked her in to her bassinette. Shortly after, we heard moaning over the monitor. As I was nursing her back to sleep, she began projectile vomiting all over me, like I had never seen before, soaking our clothing and the bed sheets. A few minutes later, it happened all over again. I called the after-hours nurse and she assured me it was all just a stomach virus. After all, “no one is allergic to rice,” she said. It took weeks before we worked up the courage to give it another try. Once again, two hours after feeding her, she began vomiting. This time it was worse. She was vomiting every 5-10 minutes. Her poor, little 5 month old body was shaking and heaving up bile. Her big sister was crying, asking what was happening to her baby sister. My husband and I were terrified- we didn’t know. She soon became lethargic, with head on my shoulder, but the vomiting continued. This time, the after-hours nurse paged our pediatrician. It was the first time we had ever heard of FPIES: Food Protein-Induced Enterocolitis Syndrome.

FPIES is a non-IgE mediated allergic reaction in the gastrointestinal system that manifests as profuse, repetitive vomiting, often with diarrhea, leading to acute dehydration and lethargy. The prevalence of FPIES in a population study in Israel was 0.3%. The most common triggers are milk, soy, rice and oat, but any food can cause an FPIES reaction. There is no curative therapy at the current time. Strict avoidance of the offending food is the basic treatment. Many children have only one trigger food and are able to eat a normal diet otherwise. Others have a few safe foods, but some don’t have any. These children rely on a diet of breastmilk (where mothers may have to eat a special diet) or an elemental medical formula. The large majority (up to 90%) of children with FPIES become tolerant of their trigger foods by the age 3-4 years.

Back to my daughter - over the next 7 months we tried a number of foods, resulting in sleepless nights, inconsolable crying, and bloody diapers. At 13 months old, she was still exclusively breast fed. I had lost 30 lbs on my restricted diet. She was losing weight and still had blood in her stool. Her specialists at Children’s Hospital in Boston told me I needed to stop breastfeeding immediately and she needed to be fed amino acid based formula exclusively for the next two months. Initially, we were denied coverage, but with the assistance of an insurance advocate, our health plan agreed to cover 80% after meeting our high deductible. She gained 2 lbs. over those next two months and showed improvements in sleep and behavior.

No tests can determine which foods will be safe for FPIES patients. You must try foods one at a time and observe. She failed every food for the first 2 years of her life. I honestly do not know what we would have done without medical formula. It has been her sole source of nutrition for the past 16 months. Her medical food currently costs about \$1,200 per month. If insurance didn't cover part of that cost, at no matter what age she needs it for sustenance, the financial strain on our already stressed family would be tremendous. FPIES affects a very small number of people in Connecticut, and an even smaller sub-set of those with FPIES are affected as severely as my daughter...but there are more families out there coping with this just as we are, and without coverage for the only thing getting nutrition into their child's body, the road ahead would be even more daunting. It is a very small cost to insurance companies for a return that is immeasurable to affected families.

I am happy to say that over the last 3 months we have found 3 safe foods. We are hopeful that she is outgrowing her FPIES, as most FPIES patients do. We are looking forward to the day we can say she no longer relies on medical food. But until that day, we are eternally thankful that she is able to maintain healthy weight and reach all her development milestones with proper nutrition through medical formula.

Thank you for your time.

\*The International Association for Food Protein Enterocolitis (IAFFPE)  
[www.iaffpe.org](http://www.iaffpe.org)