

## Steve Harris - Testimony

I'm here to tell you that this disease may not be prevented, but the pain and suffering insurance companies cause families can be prevented. It must be prevented.

There are many challenges a family experiences when a child is chronically ill. In fact, I live through them every day. There are good days and bad days. As a father, there were two things I never imagined having to explain to my child:

First, that he couldn't eat.

Second, that he couldn't play.

After many medical procedures and removing nearly every food from their diets, I had to tell BOTH my boys that the food they were eating was so harmful that they had to stop eating food. Instead, their only option was a foul-tasting formula that they would have to drink for breakfast, lunch, and dinner. This was not my choice. This was our only hope.

As an athlete, father and the coach of the Little League baseball team, I have been devastated to see my son, Dean, sit on the bench because he had braces on his legs or fractures as a result of this disease. Many people tend to think of this as just an allergy or gastrointestinal issue. This disease and, truthfully all types of severe allergies, is a nutrition issue. Because of the lack of calcium sources in his diet and the impact of so many medications, Dean suffers from bone health issues. He has suffered too many fractures. I have coached too many seasons without my favorite player on my team. Dean has missed too many gym classes and has had to spend too many days watching his brother and his friends play outside.

I wish I could say, that was all that consumed my worries, fears and disappointment. It gets worse.

Over the years, I wanted so badly to spend more time with my boys by their hospital bedsides, but I couldn't, because the only lifeline we had was my job and my insurance policy. I had the most expensive insurance policy. Yet, my provider still declined to cover my boys' medical nutrition. And so my wife and I entered a 10 week battle explaining to our insurance company that the formula was the only thing my sons could eat. This formula was the cheapest and least invasive option for both the insurance company and my family. A win-win.

We ultimately got it covered, but we were the exception. There are insurance companies that won't cover this formula, and the ones that do, can change their policies at will, forcing families to quit their jobs, relocate or work more hours.

This is a complex and serious disease. It cannot be prevented. But, the least invasive and most cost-effective solution is elemental formula. There are no other options. Yet insurance companies today, refuse to cover it and force families to spend

months struggling and fighting to feed their children, to get what they need to survive.

Parents of sick children can never stop fighting for a better life for their kids. But, with your support of House Bills 49 & 1436, we won't have to fight so hard to feed them.

Thank you.