

Good Morning. My name is Jessica and this is my husband Ryan. We are here today on behalf of our son, Oden, and all the children in Pennsylvania who depend on amino acid elemental formula to live, asking you to please pass this bill. This formula is not a choice; this formula is what our son needs to survive. Every day this bill doesn't pass, is another day a family worries about how they will pay to keep their child alive.

Our son Oden was born in September of 2012: the happiest day of our lives. Oden is a happy baby that is full of personality. He loves animals, football, and people. He also suffers from FPIES – Food Protein Induced Enterocolitis Syndrome.

We had trouble with food from day one. We decided to breast feed because of all the touted health benefits. However, Oden was losing weight when he should have been gaining it. In the first three months of Oden's life, he was in and out of the hospital and he went through a procedure, a surgery, and tried many formulas. But still, something was wrong. At one year of age we finally had an answer to what was going on, Oden was diagnosed with a food protein allergy - FPIES.

Oden tried and failed many formulas – he would have terrible rashes covering his body, would scream in pain, vomit, experience dehydrating diarrhea, and have bloody stools. But then we found our miracle. He was prescribed Elecare. The rash receded, the vomiting and diarrhea stopped, and once again, we finally had our happy baby back. Elecare solved our son's health problems – it was magical! However the formula carries a hefty price tag. Our battle for a diagnosis quickly became a battle to cover his formula.

Because he is on such a limited diet Oden gets the majority of his nutrients and calories from this amino acid elemental formula. This is a hypoallergenic formula that is extremely expensive. I cannot purchase this formula at a supermarket, I need a prescription and I need to go to a pharmacy or a medical specialty home care services store to get his food. This formula is not an option, it is a necessity for him to live; just as insulin is a necessity for diabetics.

I do not know how long he will be on this formula. I wish I did. I wish that he would outgrow this allergy tomorrow, but until that happens, he needs this formula to not only give him the calcium but the fats, proteins, nutrients, vitamins, and all the essential items his body needs that he is not getting from food. Oden's body cannot handle many foods, his body rejects it.

Even with a diagnosis, our emotional roller coaster continues. We're concerned he will accidentally consume food that is extremely harmful to him, and we fear that our insurance company will deny the coverage of his formula, leaving us – and our finances – at their mercy.

My son can only safely consume 8 foods. Eight. You see Oden is allergic to many food – milk, soy, rice, eggs, oats, wheat, chicken, bananas, peas, and the list goes on and on. We, along with all the families, exhausted every other formula possible before going on the amino acid formulas and honestly we want nothing more than for our child to be able to eat any food he wants and drink a big glass of milk. If Oden did not have Elecare, we would not have the nutrients needed for his brain to develop, his muscles to grow; in short for him to survive.

For children with FPIES, the long-term prognosis is bright. Most children will outgrow their allergies by 5– it's the first 5 years that are heart breaking and difficult. The slightest bite can cause him to get a rash, vomit, be in an incredible amount of pain, suffer from dehydrating diarrhea, and more.

I am blessed because for the next three months we received approval from our insurance company, to cover this formula, but it was a battle. But every 3 months they hold all the cards. They decide whether to approve or deny the coverage of his formula and the battle continues.

I urge you to please support house bill 49 & 1436 for the children, like Oden, and their families who suffer from the conditions that require them to consume an elemental formula so that they may live, thrive, and grow up to become successful, healthy adults. I thank you for your time and your consideration on supporting House Bill 49 & 1436.