

Allysha Zink Testimony  
House Bill 49& 1436

My daughter, Makenzie, was born May 10, 2013. She was born without complications and was given a clean bill of health. She was starter off on breast milk. After two weeks of nonstop screaming, back arching and diarrhea, our pediatrician recommended switching to formula. We tried Enfamil Newborn, that didn't work. We tried Enfamil Gentalse. That didn't work. The doctor ordered lab work and an abdominal ultrasound because she was crying every day, all day. Her bottom was getting so sore from the diarrhea. Our pediatrician couldn't figure out what was wrong. Her labs and tests came back normal. She was even put on two reflux medications and still no relief. Finally, Makenzie was put on Nutramagin. This is a hypoallergenic formula for kids with sensitivities to dairy. Makenzie seemed to have calmed down a little while on this formula, but that was short lived. Two weeks after starting the Nutramagin, she was 3 months now, the pediatrician did a hemmo-cult which tests the stool for blood. Her test came back positive. She had a GI bleed caused by a cow's milk protein allergy. Nutramagin has a very small amount of the protein in it and it was poisoning my baby. Immediately we were switched to EleCare. Our previous insurance company, Health America, was wonderful. We had 16 cans delivered to our door at 10 pm that night. They covered it 100% because it was medically necessary. After Makenzie was on the formula, we saw a drastic change. My baby was happy and smiling. After 3 months of not going anywhere in fear our daughter would just cry and scream, she was finally able to enjoy the park and outings. She was no longer in pain. We were no longer unintentionally poisoning our daughter. On November 31, 2013, our insurance changed to Geisinger. I called 8 weeks ago yesterday for a refill. I was told that the durable medical company I worked with did not accept my insurance. I called Geisinger and they gave me 18 different DME companies to call to see if they could provide my daughter with the formula. I spent two days calling the 18 companies, all of which said they did not participate with Geisinger. I called my old DME for help. They advised me Geising has their own company they deal with, Vitaline. I called Vitaline, got all the forms, prescription and letter of medical necessity sent over. Geisinger confirmed they received the info and said I would have my formula in a couple days. It never came. I called every day. Geisinger would hang up on me, pass my call off onto someone else or just say "I don't know what you want me to do." Some Geisinger employees would say it was covered, others said it's not but they legally can't deny me. I got a different story every single day for 7 weeks. I felt as though I was on a never ending hamster wheel and no one cared about my daughter. After we were denied the formula officially, I filed for an appeal. My doctor called and a peer to peer was done. I was advised that while it is 100% medically necessary, they would not cover it because she did not have an inborn error of metabolism and or was not receiving the formula via a tube. Geisinger told me to apply for WIC and state assistance. I pay approximately \$150 a week for private insurance. My baby should be able to receive her medically necessary formula with no problems. Geisinger told me that the formula coverage was not life or death, she would be fine without it. If I do not feed Makenzie the Amino Acid based EleCare, She will have a GI bleed, become anemic and need to be hospitalized. She will not receive the nutrition she needs to live without the EleCare. Geisinger laughed at me, they laughed at our plight. This is life or death for my daughter.

Last week, I received the final denial in the appeal process. I cannot fight Geisinger anymore- there is nothing left for me to do but pay the \$55 a can out of pocket. Makenzie goes through 1 can in two days. That is 3 ½ cans a week-\$137.50 a week in formula. I cannot afford that. We have no other options to try. EleCare is the ONLY option. Her health is jeopardized with any change. We looked into changing insurance companies, but because this is a pre-existing condition, no one will cover it or our monthly cost for the insurance is over \$500 with a huge deductible. If it was not for our pediatrician getting us samples from the manufacturer, we would have been forced to make the choice between

paying a bill or buying formula. The choice is clear-but no parent should ever be faced with that decision. All because of this one formula, EleCare, my daughter is happy and healthy. That is why I am asking you to please support House Bill 49 & 1436 to get this formula for other families and children.