

HB 5432

FTR

Testimony for Bill 5432: Expansion of Medical Food Coverage

My Name is Melissa Whitney and I am the mother to a fantastic little boy named Ethan. Ethan is three years old and suffers from multiple medical conditions that make him 100% reliant on Elemental formula. Ethan is not able to eat any foods at all. If it was not for Elemental formula, Ethan would most likely not be with us today. Ethan suffers from Eosinophilic Esophagitis, Eosinophilic Gastritis, Chronic Intestinal Pseudo Obstruction, Is allergic to 100% of all foods, Anaphylaxis, Gastroperisis, Severe Hypoglycemia, and a suspected mitochondrial disease. Ethan has a Gastric tube (G-Tube) and a Jejunal Tube (J-Tube). He is fed through his J tube 24 hours a day using a feeding pump filled with Elecare JR unflavored (The Elemental Formula). Ethan's medical costs are astronomical. With the increase in insurance premiums, co-pays, deductibles, co-insurance, and travel costs to see multiple specialists, it almost makes it impossible to ever be able to cover the high cost of elemental formula as well. Ethan currently consumes approximately 1 can of elemental formula per day. If we have to pay for his medically required formula out of pocket it would cost our family \$840.00 per month or \$10,080.00 per year. This would create financial ruin to our family. It is already difficult enough to raise a child with complex medical needs. There are many families like ours around the state.

Melissa Whitney

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