



Owen, Age 2

Arizona | EOSINOPHILIC DISORDERS | Immunoglobulin E & non-Immunoglobulin E-mediated allergies to food proteins | Annual costs: \$10200

Our journey began in January 2018. Owen was 11 months old and went into anaphylactic shock due to peanut butter. This was just the tip of the iceberg, over the next several months he would be diagnosed with over 20 food allergies. Even after eliminating all of the allergens from his diet he was still constantly vomiting all the time, especially at night time. Owen was not meeting his growth milestones and was beginning to lose weight. This warranted a visit to the pediatric GI. Our GI immediately wanted to schedule Owen for an endoscopy and a colonoscopy to rule some conditions out. Owen was diagnosed in July 2018 with severe EoE with >60 eosinophils found in his esophagus. We have been battling insurance for coverage since then, currently it is March 2019. It makes no sense why we have to spend so much time and energy to fight insurance as well as tons of money (that we don't have) for Elecare Jr, Owen's only safe food, when we pay so much per month for our health insurance and live in a state where it is mandated for insurance to cover his Elecare Jr. Something needs to change! Our health insurance is "private pay" provided through my husband's employer. Although we have United Health Care, the policy comes through Valley Schools and therefore goes around Arizona's state Statutes-ARS §§ 20-826.03, 20-1057-10, 20-1342.05, 20-1402.02, 20-2332

(<http://www.azleg.gov/legtext/47leg/2r/bills/hb2364h.pdf>) So even though we live in a state which mandates coverage for amino acid-based formula with a diagnosis of EoE, our insurance does not have to cover it. It is just another loophole insurance companies get around. We pay more per month for my son's food (Elecare Jr.) than we pay for our home mortgage. Our policy states: Food of any kind. Foods that are not covered include: Enteral feedings and other nutritional and electrolyte formulas, including infant formula and donor breast milk, even if they are the only source of nutrition and even if they are specifically created to treat inborn errors of metabolism such as phenylketonuria (PKU). Infant formula available over the counter is always excluded.

Foods to control weight, treat obesity (including liquid diets), lower cholesterol or control diabetes. Oral vitamins and minerals. Meals you can order from a menu, for an additional charge, during an Inpatient Stay. Other dietary and electrolyte supplements.

Owen depends on medical nutrition to stay healthy. Owen and thousands of others across the country are depending on you to co-sponsor the Medical Nutrition Equity Act. Please contact the offices of Sen. Casey, Rep. McGovern or Rep. Herrera Beutler.