



Dear West Virginia Lawmakers,

These are the stories of some of your West Virginia constituents whose doctor-ordered treatment includes medical nutrition. These constituents, and thousands of others, rely on medically necessary nutrition to survive and are counting on you to co-sponsor the Medical Nutrition Equity Act.

West Virginia has a state law governing medical nutrition, but it has the following exceptions*:

- **Private Insurance:** No Coverage
- **Public Insurance:** Limited to certain diagnoses and to formula only

PATIENTS & PROVIDERS FOR MEDICAL NUTRITION EQUITY

<https://nutritionequity.org>

* State-by-state coverage based on data from the National Coordinating Center for Regional Genetics Networks' 2016 report in cooperation with the Catalyst Center, updated July 2017 and the National Organization for Rare Disorders (NORD) State Report Card 2018.

Jeremiah, Age 7

EOSINOPHILIC DISORDERS



Our family is currently affected by having to pay out-of-pocket for medically necessary formula (Elecare, Jr) for our now 7-year-old son. Jeremiah was diagnosed with Eosinophilic Esophagitis (EoE) back in June 2013. Prior to his diagnosis, he was very sick for 5 months. During those 5 months, we had documented over 20 doctors visits that left the doctors unsure about what was wrong with him. Our child was vomiting daily, unable to keep his food down and there was just no explanation of why he was not developing. He was eventually put into the hospital for severe malnutrition and had to stay for 9 days to regain his strength. At 15 months old, a child who could only sit up, came home crawling for the first time. The formula he was given in the hospital helped give his body the nutrients it needed. Without this formula, our son would not be able to thrive today.

For over 4 months we fought with our insurance to pay for this medically necessary formula and were denied 3 times. One of the reasons we were told by the insurance company was because he didn't have a feeding tube. If he had a feeding tube, it would be covered. Thankfully, our son can deal with EoE without having to be attached to a feeding tube. He has been on this formula for over 6 years now without any help from our insurance.
