



Dear Oklahoma Lawmakers,

These are the stories of some of your Oklahoma 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.

Median annual cost for Medical Nutrition for Oklahoma residents featured here: \$4260

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

- **Private Insurance:** No Coverage
- **Public Insurance:** Limited by diagnosis 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.

Marcella, Age 15

EOSINOPHILIC DISORDERS

Annual cost: \$4,320



Marcella was diagnosed with multiple food allergies in 2016. She is allergic to soy, peanuts, tree nuts, fish, shellfish, along with a slew of environmental allergies. We have lost count of how many times we have had to administer epinephrine, hospital visits and ICU stays due to her severe allergies. She began having unexplained allergic reactions, vomiting, chest pains, horrible stomach pains and loss of blood and blood in stools. Her hemoglobin dropped overnight. She had food impactions and trouble swallowing even liquids. A swallow study was done and confirmed a hiatal hernia so she was referred to GI. She was then diagnosed with Eosinophilic Esophagitis and Sphincter of Oddi dysfunction. She was put on an elimination diet of the top 8 foods and started on the slurry of budesonide. She went into remission in June 2018 and we were given the OK to re introduce wheat, dairy and eggs with caution. Within months of reintroducing these foods she immediately fell out of remission and had noticeably more significant difficulty swallowing and uncontrolled vomiting episodes. She was last scoped for her 3rd time on January 21, 2019. Recurring Eosinophilic Esophagitis was confirmed. She was started back on the budesonide slurry once again. Along with the Top8free diet we hoped to be able to get her back into remission. Her GI also prescribed Elecare Jr as a nutritional supplement due to severe food allergies and Eosinophilic Esophagitis causing food impactions, difficulty swallowing, loss of appetite and weight loss. She is also suffering significant hair loss. Her GI prescribed the Elecare Jr to be taken orally 2 times daily. Marcella has SoonerCare insurance. They do not cover oral use of Elecare Jr which she desperately needs. Marcella and every other person should have the right to coverage for the Elecare Jr whether it be taken orally or through tube feeding. Please help my daughter she is only 15 ☐. Marcella has SoonerCare and they do not cover Elecare Jr if it is taken orally. Our insurance does not cover for my daughter to receive the nutrition she do desperately needs.

Ezra, Age 3

Annual cost: \$4,200

The formula is very expensive!...My Grand-daughter and her husband both work and with all the bills cannot afford the formula (which is relevant in this disease)...Please everyone who reads this..sign the paper for our government to help with this !...these kids and adults will not ever get to eat some of the foods we eat...they will basically be vegetarians all of their life!...Please, please, help us with this....thanking you very much..
