



Dear Nevada Lawmakers,

These are the stories of some of your Nevada 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 Nevada residents featured here: \$3300

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

- **Private Insurance:** Limited to certain diagnoses and nutritional delivery methods, and to formula only; Self-Insured Completely Exempt;
- **Public Insurance:** Limited to certain diagnoses and by age, 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.

Liam, Age 5

EOSINOPHILIC DISORDERS



Liam has struggled with GI issues, food avoidance, and maintaining growth since he was born, but the issues intensified once we tried to start introducing solid foods. His pediatrician told me time and time again that we just needed to be patient, but things continued to worsen. We have spent the last 4 years struggling to deal with his symptoms before he was diagnosed with EoE five months ago. In addition to following a restrictive diet since 16 months old, his dietitian and allergist advised that he eliminate all citrus, peanuts, and tomato this past fall. Then, three months ago, we had to eliminate potato, which has been very challenging since potato starch is an ingredient in most gluten free products. As we have had to continue to cut foods, thereby increasing the frequency he is eating a small variety of foods, we have noticed his symptoms reemerge more quickly and with much more intensity. He has been on a steroid treatment for the past three months, but his specialist team has advised that following an elemental diet will most likely be our next course of action. Due to my husband's military service, we have not always been able to have and maintain the level of quality medical care that we would want for our son. Knowing that medical nutrition would be fully covered, without question, would be a huge burden lifted off our shoulders as we very soon may not have any other options if Liam is to ever have a pain free day in his life and actually grow. We have TRICARE, and I have been told it is fully covered by our insurance as long as it is filed as a separate referral and includes very specific terminology. However, since he has not started yet, we don't have any experience with it firsthand.

Pamela

Homocystinuria

Annual cost: \$3,600



It would mean so much to have the medical nutrition equity act passed. I have a diagnosis of homocystinuria which was discovered very late in life. I have suffered from strokes and blood clots in my lungs because of it. Although I currently have coverage through our insurance, it is always a fight to get them to pay. It requires many frustrating hours of appeals and mountains of documentation from my doctors. When I turn 65 in a few years and am eligible for Medicare, I will lose coverage for medical nutrition. I will then be forced to pay \$800 - \$1000 a month to receive these necessities to stay healthy. This is of great concern to me. Please pass this legislation. I am a person, not just a diagnosis to be forgotten!

Sabastian

Maple syrup urine disease

Annual cost: \$3,000

It is really hard to have a child with a metabolic disorder. I pay over \$600.00 per month for insurance coverage, It was

prior to Obama Care \$1200.00 per month. This does not leave me much funds left over to buy medical Nutrition food, my insurance covers the formula which is so expensive. There has been month's where we did not have the extra funds to purchase the metabolic food and it has affected his ability to maintain his decent levels. Sabastian had a hard start since the hospital lock his PKU stick and could not find it for months even after he was lying in the hospital trying to be diagnosed. There has been several times during his life where i lost coverage for him which almost caused me to quit my job as i never could afford the over \$600.00 a can his formula cost, he using two a day.

If we would have the right to order an cover medical nutrition it would relieve the fear and stress involved in managing his MSUD with out the coverage.
