



Dear Louisiana Lawmakers,

These are the stories of some of your Louisiana 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.

**Average annual cost for Medical Nutrition for Louisiana residents featured here: \$6300**

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

- **Private Insurance:** Limited to certain diagnoses, Self-Insured Completely Exempt;
- **Public Insurance:** Limited to certain diagnoses

**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.

# Venetia

## Phenylketonuria (PKU)

**Annual cost: \$6,000**



I have to be on Medicaid because I can not afford to get insurance on my own or thru my employer and it is very difficult to make ends meet because the food costs way to much for me to buy it out of pocket. It would help me out tremendously as I am also a single mother of a 10yr old boy. I would to be able to have coverage for my medical foods. It would a lot of stress off my mind to not have to worry about how I'm going to afford them and food for my family as well.

# Tyson, Age 7

## Phenylketonuria (PKU)

**Annual cost: \$6,000**



It's very important having coverage for medical nutrition. We could not afford to pay out of pocket and have no private insurance. If, We didn't have the state of Louisiana and Medicaid our child would be severely permanently brain damaged and institutionalized in a state run nursing home and/hospital. The picture attached is Tyson with his BioMarin case manager at a PKU Pantry in New Orleans recently. The food on the tables are examples of what Tyson can eat. They are not cheap! A loaf of low-protein bread with maybe 10 slices cost us \$5.69 each! Medicaid covers Tyson's medical formula and KUVAN. It does not cover any low protein foods.

# Claire, Age 8

## Tyrosinemia

**Annual cost: \$6,900**



I want to introduce you to my eight-year-old daughter, Claire. At first glance Claire appears to be a normal 2nd grader. She loves playing soccer, gymnastics, and playing with her brother and sister. She's silly and funny and just a joy. What you don't see is that she has an extremely rare metabolic disorder called Tyrosinemia Type 1. We were very lucky that her disorder was discovered through newborn screening. Louisiana expanded their testing two months before she was born. Without this expanded screening, her outcome could have been fatal.

So, what is Tyrosinemia? Basically, Claire's body does not properly break down the amino acid, tyrosine, which is a building block of most proteins. Since the tyrosine cannot be broken down, it becomes toxic to her body. This can cause liver and kidney failure, softening and weakening of the bones, problems affecting the nervous system, and increased risk of liver cancer. The medically necessary treatment for Tyrosinemia Type 1 is a low protein diet, a metabolic formula, and medication. Specifically formulated low protein foods are essential for necessary calories and for ensuring an adequate

quantity of food, as well as, providing variety and increasing quality of life. The metabolic formula provides the necessary protein, calories, and other nutrients in a form free of tyrosine. This is a lifelong disorder. There is no cure.

What does it mean to have a “low protein” diet? The low protein diet has two components: food and formula. For example, Claire can only have 10 grams of protein per day. My cell phone is about the size and weight of a 5-ounce piece of chicken. This would be 38 grams of protein ... 4 days’ worth of food for Claire. This illustrates why it is so important that patients with metabolic disorders have access to low protein foods. Unfortunately, the cost of low protein foods can be very expensive and not uniformly reimbursed by health insurance, resulting in a large financial burden on a family. For example, a bag of low protein pasta is \$16, and a bag of veggie meatballs can run around \$24. And shipping these special foods can be very costly as well since you can’t pick them up from your neighborhood grocery store. Then there’s the metabolic formula. A case of 6 cans is about \$500 and we use about 1 case per month...\$6,000 per year.

Many states do not assist in formula coverage and do not require insurance to cover medically necessary foods and formula. Some states only cover certain metabolic disorders like PKU, while other states cut off coverage to males over age 21 years. This is dangerous, inconsistent, and unacceptable. This is a diet for life. Claire depends on medical nutrition to keep her healthy and growing.

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