



Dear Tennessee Lawmakers,

These are the stories of some of your Tennessee 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 Tennessee residents featured here: \$37800**

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

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

**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.

# Jessica

## Phenylketonuria (PKU)

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



If there were no issues with getting medical formulas and medical foods, the stress of worrying would go away. As a child, we had no medical coverage for formula, and so my parents had to pay out of pocket for me and my little sister. Money for medical food wasn't even a thought when I was growing up. I had to postpone getting married until we had good insurance because we would not have been able to afford formula, let alone the food. I have always paid out of pocket completely for food, except in the last year. My insurance allows me to spend 500\$ per month on food, which is amazing! Even though this exists, I have a fear that they could take it away next year, or the next year. I always have a worry about if I was to change jobs, that the next companies insurance would not be good enough. I always get anxious with EOB's come back from insurance saying that I have a portion of the bill that I need to pay, which should never be the case. As a woman who has been pregnant twice and has breastfed, there should have never been a worry that I would have to go without protein vital to mine and my child's growth and development. Having no doubt of coverage in the future would be so important for my physical and mental health. Having no worry about having to pay an outrageous amount of money to get food and formula needed for me to be at my most focused, healthy self would be one of the biggest blessings my family and I could receive. Currently, I get 100% paid for some medical formula options, and then \$500 worth of medical food per month.

# Ellis, Age 12

## Phenylketonuria (PKU)

**Annual cost: \$4,200**

We have been fighting insurance and coverage since Ellis was diagnosed. It is very time consuming and difficult to work with insurances for her medical necessities. We have spend hundreds of hours on the phone, writing letters and working with her doctors for our insurance to provide the medical nutrition needed for Ellis to stay at her healthiest. Each year, we have to meet our \$2,600 deductible for Ellis before insurance provides support.

# Sarah

## Phenylketonuria (PKU)

**Annual cost: \$37,800**



My name is Sarah. Im 24 and I have classical PKU which means my enzyme in my liver has a hard time fuctioning breaking down phenylalanine. I've always had struggled with keeping my phe levels in range. Which when they are high create severe brain damage over time. Low protein foods and forumla are essential to living with PKU. My medical insurance does not cover any costs. As an adult its so much harder because the cost of treatment is way more then what I can afford. Being constantly rejected for financial responsibility as heath insurance is very frustrating. I'm also 25 weeks pregnant. Its

crucial for me to have access to my formula and low protein food. Without it, I can not maintain my phe levels between 2 and 4 to ensure my baby will not come out with birth defects or have a miscarriage. Even life after the baby is born will be tough trying to cover the baby's needs and my needs.

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## Zoe, Age 4

### Phenylketonuria (PKU)

**Annual cost: \$4,200**



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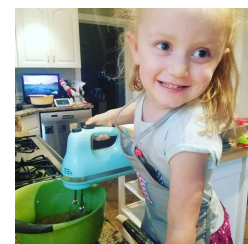
We adopted our beautiful daughter Zoe three months ago from China. We did extensive research on PKU and prepared ourselves the best we could to meet her needs. We live in TN and I was happy to see that formula would be covered. Our insurance covers formula once we have met our deductible and out of pocket. We have 70/30 coverage with Cambrooke foods once we have met our deductible. What I did not understand was that the cost of formula is only covered after you meet your deductible and out of pocket. We were also able to get 70/30 coverage with Cambrooke foods through our insurance, but only after our deductible is met. This means that we are spending about \$350 a month on formula and medical foods and will most likely not meet our deductible and out of pocket expenses in a calendar year. I am a violin teacher and I cut back on my teaching so I could spend more time with Zoe and her sister whom we adopted in 2016. Money is tight with my reduction in income and the fact that we have finalized two adoptions in two years. Having Zoe's formula and medical foods covered would make a big difference to us and give us some breathing room financially.

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## Isla, Age 5

### Phenylketonuria (PKU)

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



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Having coverage for medical foods that my daughter requires is necessary for her success of her diet management! Without the only known management for PKU (low protein diet) my daughter would incur severe neurological issues and inability to complete daily tasks. With coverage of medical nutrition would alleviate the unnecessary stressors of the only treatment for PKU and as my daughter gets older would promote her to stay on diet for life that is required!

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