



Emily, Age 6

Georgia | Phenylketonuria (PKU) | Annual costs: \$18000

Our Emily was diagnosed at 9 days old with Phenylketonuria (PKU). During the last seven years of her life we have had insurance completely deny her medically necessary formula after the age of 12 months. We have appealed, fought, had countless meetings and phone discussions, and even persuaded our provider to include phenylketonuria/inborn errors of metabolism on their plan. The benefits aren't great but they were better than nothing. One can of Emily's formula is \$100 without any coverage. She requires twelve each month. They absolutely will not cover any medical foods (with a Phe tolerance of 300mg a day of phenylalanine, medical food is essential to our daughter being adequately fed and feeling full at the end of the day) and cover only 60 percent of weekly blood draws our lab at Emory uses. We have had to make unfortunate sacrifices in order to cover such costs (\$800 coinsurance for food, \$450 coinsurance for labs, and \$250 or less of medical food per month because we are self pay). Our family of four is committed to helping our youngest daughter, Emily, so that as an adult she will not be faced with the difficult decisions that our family has had to make. Even though our family is fortunate with wonderful jobs and salaries, it puts a financial strain on us as a whole. The medical nutrition equity act would allow us the opportunity to say yes to more such as fostering sweet Emily's passion for cheer-leading and the outdoors or our oldest daughter's love for basketball and music, instead of having to front thousands of dollars per year in medical costs for one member of our family. This is a family who would be most grateful for your diligence and part in passing the Medical Nutrition Equity Act.

Emily depends on medical nutrition to stay healthy. Emily and thousands of others across the country are depending on you to co-sponsor the Medical Nutrition Equity Act. Please contact the offices of Senator Grassley or Representative Herrera Beutler today.