



Lucy and Lucas, Ages 6 and 3

Colorado | Phenylketonuria (PKU) | Annual costs: \$6000

I have three children, my six-year-old twin daughters Lucy and Lily and my three-year-old son Lucas. Lucy and Lucas were diagnosed at birth with PKU, a rare, inherited metabolic disorder for which there is currently no cure. Their livers are missing an enzyme that breaks down one of the essential amino acids found in all protein, phenylalanine or phe for short. If left untreated, phe would build up in their brains and cause severe, irreversible brain damage leading to mental retardation and a host of other neurological issues. Treatment for PKU consists of a very restrictive, low-protein diet which is supplemented by medical formula (which is stripped of phe that provides the remaining essential amino acids and calories they need) and specialty medical foods specifically manufactured for the treatment of PKU. Outside of the stigma my kids face at school from eating foods that look and smell different from what their peers are having, these foods are very expensive. While they are able to eat all fruits and most vegetables along with a limited supply of products available at our local grocery store, we must rely heavily on these specialty foods. We currently spend an average of \$500 month on these foods. While my husband and I make a good living, what keeps us up at night is worrying about how our children will someday be able to afford to feed themselves. The majority of twenty-somethings who finish college or other career training are offered lower pay when entering the full-time workforce. Spending \$500+ per month on specialty food in addition to all the expenses associated with living on one's own simply isn't sustainable. My husband's employer covers my children's PKU medical formula, which costs almost \$3,000/month after our \$3,800 deductible. However, it does not cover the cost of their PKU medical foods which is currently costing us \$500/month. I anticipate this cost will increase as my children, who are currently six and three years old, grow and increase the quantity of food they consume. Passage of this bill would mean we don't have to worry about how to afford to feed our kids, and all the others like them, now and in the future.

Lucy and Lucas, Ages 6 and 3 depends on medical nutrition to stay healthy. Lucy and Lucas, Ages 6 and 3 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.