



Breeze, 6

Colorado | Phenylketonuria (PKU) | Annual costs: \$2400

My daughter Breeze, was born with a metabolic disease, called PKU. PKU is a rare genetic disease. She is 1 of 15,000 PKUers living in the United States. We have medical insurance. I have spent hours on the phone with insurance about PKU medical coverage. I have filed formal complaints with our insurance about coverage. Insurance does not pay for ALL the care that is deemed medically necessary for PKUers. PKU food and formula is very expensive. Being off diet is more expensive, and catastrophic to the PKUer.

Imagine for a moment that your child is about to graduate from college, with honors. She is offered her dream job in an amazing location, across the country. The cost of living is kind of expensive, but roommates could make it feasible. You and your child google everything about this location, and she loves it. You look online at possible rooms to rent, figure out the public transportation to and from work. Then the health insurance information from the new job is sent over, after a few calls it seems it that your daughters dreams, are slipping away, for no other reason but insurance coverage. The insurance plan does not cover formula or low protein food. Formula alone is over \$1000 a month, and low protein food(bread, rice, pasta, low protein egg, tortillas) could easily be \$300 a month not including any fruits or vegetables.

The trajectory of my life would look completely different if there had been limits to where I could move based on if I had \$1300 a month to pay for food and formula. When I graduated college my grocery budget was \$200 a month. Some weeks we had ramen every night to save money for something fun. This is not ever an option for a PKUer. Going off diet can and will lead to many more issues, like needing pharmaceutical drugs (which ironically are paid for, but if they were on diet they would not need) losing employment, going on welfare, being institutionalized.

This so called 'Freedom' in this country does not apply to those living with PKU. My daughter should have the same opportunities as anyone else growing up in this great state and country. But right now, insurance companies have the power to limit her life. This is not right. Please be a representative for ALL the people in this state and support this bill.

Breeze depends on medical nutrition to stay healthy. Breeze and thousands of others across the country are depending on you to co-sponsor the Medical Nutrition Equity Act. Please contact the offices of Sen. Casey, Rep. McGovern or Rep. Herrera Beutler.