

When Garrett was born at 9 lbs 4 oz, we could not have been more thrilled to have a such a fat, happy baby! When we received the call two weeks later that he tested positive for PKU, we were absolutely heartbroken. What did it mean that if this beautiful baby boy consumed too much protein, that he would end up with brain damage and severe disabilities? Being born with, or having a child with PKU is like joining a club you didn't want join. However, as a parent of a PKUer, you pour yourself out to provide the best care you possibly can. The financial, physical and emotional burden is heavy. Everywhere I went with Garrett the first 5 years, I carried a smaller cooler of his formula and medical food. These medical foods are absolutely essential for a PKUers diet and also incredibly expensive for an average family- \$12 for small bag of pasta. They can only be purchased through the hospital or a few online retailers, where families incur the additional cost of shipping.

When Garrett about 6, we started a medication that has allowed his body to process more protein. Therefore, he can eat some rice pastas and breads, almost eliminating the need for the medical foods. For this we are so grateful, but recognize that there are so many PKU kids that cannot increase their protein intake with this medication, thus relying heavily on medical foods.

We have always had coverage for formula and Kuvan (with the help of NORD) but have never had coverage for low protein foods. Garrett is on Kuvan and mostly eats GF pastas and breads instead of the medical food, but if he was no longer on Kuvan, he would need to purchase a lot of low protein foods. We are currently shopping for private insurance (husband left his job and started a new one a couple months later) and we are forced to find a top tier insurance plan because we need the best coverage for him, which would still not cover any foods.

We are currently shopping for private health insurance, and as a family of 6 with one PKUer, our premiums are extremely high. We must buy a top tier plan if we want coverage for Garrett's frequent blood draws, formula and specialist visits. To think that at over \$2300 a month in premiums, our insurance would not help cover medical foods is deplorable. Coverage for medical nutrition would alleviate a huge burden off PKU families, and would allow PKUers better access to the foods vital to protecting their brains from damage.