

Having a child with PKU is extremely time consuming! I am always preparing special food for him and making sure he has what he needs to continue to grow. As we get closer to him turning 5, our only option is for me to go back to work. I have been doing a part-time at home job where I can, but as we get closer to paying for his formula, I will need to get higher paying job that will require more time. I feel a lot of anxiety worrying that my son will always have this struggle even as an adult. This diet never gets easier! Every meal is planned and every meal is at a price. I will do whatever it takes to ensure my son has what he needs to maintain a healthy life. Getting financial help relieves some of that stress and helps me to focus on the day to day meal planning that is required. Currently, my son is eligible for help with his formula through a metabolic program until he is 5. He will be 4 next week so it's getting really scary for us because next year, we will need to cover all costs out of pocket. That's \$800 for just his formula not including the medical food we purchase regularly. This price is only going to go up as he gets older. I have already contacted our insurance a few times to possibly get help with the high priced low protein food we need to buy and every time, it gets denied. Sadly, I think it is due to the lack of knowledge they have on this disease. If they understood the consequences of not being able to have this nutrition, I would hope they would cover it.