



## Saylah, Age 2

**Kansas | Phenylketonuria (PKU) | Annual costs: \$2400**

My daughter has a milder form of PKU and therefore does not need as much formula to live a healthy life. However, as she gets older her body will need more natural protein, at which point she will need more formula to function successfully. More formula means more money. As I read the stories of her fellow PKU'ers my heart breaks. How helpless families must feel who struggle endlessly, or worse yet, are unable to provide for medical necessities. Our health insurance covers so little that it actually makes it more cost effective for us to pay cash, out of pocket for our daughter's formula. These children hold a lifetime of battles before them that most will never have to bear. Let us all fight to help carry a little of their burden. Their fight won't only be about delicious food they will never be able to eat (or more accurately - never being able to consume most food in the human diet) but about psychological and financial battles they will need to fight and win in order to be happy and successful. Finally, treating this condition successfully takes TIME. Low protein recipes and foods that are even somewhat palatable are not easy to come by. I spend more time in the kitchen preparing foods than I could have ever imagined. She will carry this daily inconvenience into adulthood with her. TIME takes away from work, from family, from life. Let's not add a large financial burden to the top of their mountain of hurt. I see change and see it soon.

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Saylah depends on medical nutrition to stay healthy. Saylah 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.