



## Jackson, Age 6

**Kansas | Phenylketonuria (PKU) | Annual costs: \$3600**

We reside in Kansas. Our son Jackson was born June 12, 2012, 5 days later the State of Kansas called with positive results for PKU from Jackson's newborn screening test. I initially worked company that covered medical nutrition until Jackson turned 12 months. The co-pay was still high, once Jackson turned 1, they stopped covering! This was devastating to us and our family. We fought insurance, we contacted our local news company and we also started a petition. After several months Jackson's medical beverage was covered. My employer changed insurance companies and again we had to fight and educate the employer about PKU and the required treatment. They were exceptional and actually changed their policy. I now work for a company that does not provide any coverage, nor does my husbands. The fact that we among many other families are faced with the possibility of not being able to afford our sons medical beverage is beyond terrifying. PKU is a life long disorder, the cost for insurance companies to cover the cost medical beverage is for more cost effective than them having to pay for the illnesses and complications to follow without medical beverage. We want nothing more than our child and future children to have the access to their only FDA approved treatment without having to worry about medical nutrition. Our son has every chance of being functional and educated human being, but without his medical nutrition he is highly likely to be the complete opposite. Insurance companies should be covering PKU treatment! It is a pre-existing condition. As a health care provider myself, I see many non-compliant patients getting coverage without any questions asked, this is devastating especially to these children and families that so desperately needing coverage for medical nutrition. We are begging and praying for our congress to make this right and not withhold coverage for medical nutrition. It would be considered unethical to not support this bill! If every state mandates Newborn Screening on every newborn child, then every state should mandate insurance to cover the treatment.

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Jackson depends on medical nutrition to stay healthy. Jackson 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.