

When our firstborn was just 7 days old, we received a call to rush him to the hospital. He had tested positive for PKU. We, including extended family, had never heard of PKU. The beginning of our journey was filled with concern for how our child would grow and if he'd be able to have a normal life. We got into a routine, and things began to feel normal. We had a second child, and he also ended up having PKU. But we were experienced in the care of this genetic disorder already, so we were able to be happy that the boys had each other. Before our second child's first birthday, we received notification that our insurance would no longer cover the completely necessary medical beverage that was keeping my boys healthy and allowing them to grow without brain damage. We were informed that the state of Kansas does not mandate coverage of PKU, so the insurance didn't have to cover it. My husband is self employed, and we had no other options. The only thing we can do, other than move to a different state, is make sure we do not make enough money so that our boys can be covered on Medicaid. Without Medicaid, our sons would not be able to go to the children's hospital for care with the genetic team that has helped them grow and thrive since their first days of life, we wouldn't be able to afford the medical beverage they have to drink (a 6 day supply for them both costs over \$300), and we'd have so much out of pocket costs to keep our kids healthy that we would certainly be bankrupt. And then there's the food! My children can only eat around 5 grams of protein a day. It is impossible to fill growing boys on natural foods and stay under 5 grams of protein. That means we purchase lots of specialty low protein items monthly. They live on their special pasta, meat alternatives, and specialty breads. They're so happy when they can have food that looks similar to what everyone else eats. How do I explain to my boys that a completely treatable disorder is not being covered? If I didn't give them their medical beverage or low protein foods and allowed their brains to become damaged, then they would be cared for in an institution. That would be covered. There is no way I would ever allow that, but surely you see the irony! Please help make a way for our children to have the basic rights and future they deserve.