

When Norah was just 5 days old, we received a call from our clinic saying that Norah had something called PKU. At the time, we had never heard about PKU and did not know what the future would hold for us. Shortly after our first visit we had to order our first order of medical formula. At the time my insurance was a self funded plan and they did not want to cover her formula because she was not fed through a tube. As a mom, whose only concern is making sure that my baby is healthy i could not believe what i was hearing. The insurance company was going to determine what my child could have access to, even though her clinician was saying it would be detrimental to her health if she did not receive this formula. We battled this for months until it was finally approved. Once the approval came through, we were still paying almost \$200 per month just for formula. Once she started eating solid foods, and we had to start ordering through the low protein food companies, we were placing orders, some of which would come to \$300 just for the basics (pasta, breads, sauce). Now that she is older we have to do a lot more food from the grocery store, which means she can't have the treats like homemade brownies and cakes because we can't afford to spend that much on ordering her food. Norah was finally approved for Medicaid last year, which fortunately covers her formula, but does not cover her food. I worry for my daughter that when she is on her own insurance she is not going to be able to afford to stay on diet and it is going to hurt her severely. A parent should not have to worry about their child not having access to something that is so important to their health. You should worry about what college your child will go to, or what career they will choose, you shouldn't have to hope and pray that they have access to good insurance just to stay healthy. Having coverage for medical foods, means that i could have the "normal" worries that every parent has for their child's future.