

As all parents who experience it, we were overwhelmed once we got the call, at 5 days of age, that our daughter Maeve had been diagnosed with a rare metabolic disorder requiring a strict medical diet in order to prevent irreversible brain damage. As the ones responsible for preventing this and keeping her healthy, we had to spend a lot of time and effort taking her to frequent appointments, drawing blood, and learning how to safely feed her.

For the first 6 years of our daughter's life we were lucky to live in California where there is a state mandate for both formula and medical food coverage. Aside from our monthly premiums for our employer-based health insurance, the food and formula Maeve required to stay fed and healthy was covered 100%. However, we recently moved to Texas, where there is no state mandate for medical foods and we pay an expensive co-pay each month for formula. The move has created a financial burden for us, and we know there are families who have an even harder time purchasing what they need to prevent catastrophic results of an untreated diet. Looking back, I can't imagine having a huge financial burden on top of being overwhelmed with all that came with the initial diagnosis.

Level of care for PKU and related disorders should not vary based on which state you live in. It is clearly in everyone's best interest to support individuals and families with simple diet management rather than having to help meet the needs of individuals with severe disabilities that could have been prevented.