Our 10 year old daughter Marisa has Phenylketonuria (PKU). She is only able to have 5 grams of protein a day from regular foods. She gets 40 grams of equivalent protein from her medical formula a day. She does not complain about not being able to certain foods and likes the special medical foods and formula. She does a great job with staying on the her low protein diet and eating only what is allowed on her diet. The special medical foods and the formula help give her the protein and nutrients she needs, plus helps to make her feel full and satisfied. Without the formula or special medical foods, she would not receive the nutrition she needs to live a healthy life and it helps her cognitive functioning as well. The Medical Nutrition Equity act would help us and others so much. The medical formula and special medical foods that our daughter needs are expensive and difficult to afford without assistance. Our daughter’s formula alone is about $200 a can and our daughter needs 10 cans a month. Our insurance has denied all of our claims for this formula, but yet we are in a state that has legislation stating that formula is to be covered by insurance for those with PKU (IC 27-13-7-18). That makes the cost of the formula $24,000 for a year. That is definitely a hardship for us. Plus we also need to purchase medical foods which need to be sent away for since local stores do not carry these types of foods and that is over $1000 a year for us. We pay $670 a month in insurance premiums but they won’t cover the medical formula. Our deductible is so high that even if we had a copay, it would still be difficult to pay for the formula. A representative from our formula company is working with our insurance company to find out why they are denying our claims. The insurance company is saying that the contract we have with them does not cover the formula. But we live in Indiana where insurance is supposed to cover the formula. IC 27-13-7-18.

This is such an important issue. If we didn’t have all of these expenses, we would be able to have our daughter participate in activities that she enjoys. It would lift the huge financial strain on our lives. We worry for our daughter as she becomes an adult and has to try to cover these expensenses on her own if there is no help for her. We need this Medical Nutrition Equity act so that our daughter and others will receive the nutrition they need so that they will remain healthy.