



Hattie (20 months) and Maxine (6 months)

Pennsylvania | Phenylketonuria (PKU) | Annual costs: \$7200

We have two beautiful daughters, Hattie (20 months old) and Maxine (6 months old) who were diagnosed with PKU at birth. Because of their PKU both girls require medical formulas in order to grow and develop on par with their peers. They also require an extremely restrictive diet with limited protein (approx 6 grams per day, equal to 2 pieces of bacon). As they grow and their appetites increase we will have no choice but to purchase special medical foods in order to keep them healthy and well fed. These foods will cost us over \$500+ per month completely out of pocket. We are lucky that the state of PA requires coverage of their formula and blood labs, otherwise we would have to pay out of pocket- each can of formula costs roughly \$125, they require 12 per month and labs could be upwards of another \$1000 per month or more. While our family will make the sacrifices needed to provide our daughters with whatever they require to keep them healthy this does not relieve the anxiety about how they may be able to handle the burden of their conditions when they are adults and may not have coverage. Inherited Metabolic Disorders are not a lifestyle choice, they are a medical condition that REQUIRES these foods and formulas to live. It is enough of a hardship to manage these conditions, the Nutrition Equity Act would at least lift the strain of cost for so many who struggle to pay for the necessities to keep them healthy. We are lucky that the state of PA does cover our girls medical formula costs however they do not cover any of their medical foods. If we didn't have the coverage that we do our out of pocket costs would be nearly \$2500 per month, potentially higher.

Hattie and Maxine depends on medical nutrition to stay healthy. Hattie and Maxine 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.