



## Mabel, 10 months

### Massachusetts | Phenylketonuria (PKU)

Mabel was diagnosed with the metabolic disorder, Phenylketonuria (PKU) at birth. She is thriving with the help of her metabolic formula and a very low protein diet. Without a very low protein diet (right now she is allowed a half gram of protein per day on top of what she gets from breastmilk) and metabolic formula, Mabel would be irreparably brain damaged within a few months. We are very fortunate in Massachusetts to have laws in place that make it mandatory for insurance companies to cover medical formulas and medical food for people with metabolic disorders. One month of Mabel's formula is approximately \$200 without insurance, and will increase as she gets older and requires more on a daily basis. The medical food is extraordinarily cost prohibitive without insurance. A box of pasta, for example, is around \$12. If we did not have coverage in MA, I would have to choose between my child's brain development and paying my mortgage or my electric bill--or feeding the rest of my family. People in many other states, and even people in our state with self-insured policies, are not so lucky. Many other states do not offer any coverage for formula or food, or only cover formula, or only up until age 18. These metabolic disorders do not disappear. They are genetic and life-long with severe consequences for those who are not able to remain "on diet" and consume their formula.

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Mabel depends on medical nutrition to stay healthy. Mabel 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.