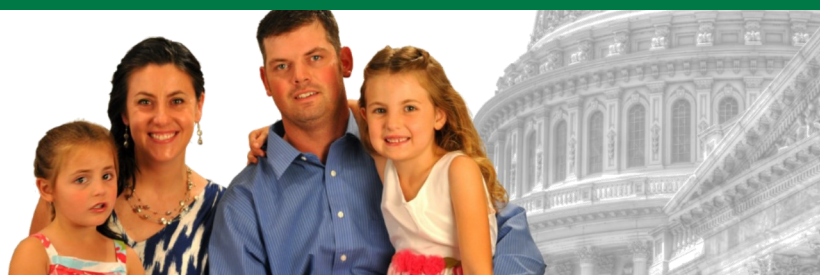




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Why treating PKU is important:

- Phenylketonuria (commonly known as PKU) is a rare, inherited metabolic disorder that causes intellectual disability and other neurological problems without treatment.
- The medical foods required to treat PKU cost approximately \$12,000 - \$15,000 per year, which is far beyond the means of most every PKU family. The cost of not treating PKU, however, is much greater. Caring for an untreated PKU patient is at least 8 times more expensive.
- An untreated child with PKU can lose 4 IQ points each month and will suffer severe and irreversible intellectual disabilities before reaching toddlerhood.
- Children and adults who are not on treatment also experience many other medical issues, including depression, impulse control disorder, phobias, epilepsy, tremors, and pareses.
- Women with PKU must maintain strict metabolic control before and during pregnancy to prevent fetal damage. Children born from untreated mothers with PKU may have a condition known as "maternal phenylketonuria syndrome", which can cause small brains, intellectual disabilities, birth defects of the heart, and low birth weight.
- PKU and other Inborn Errors of Metabolism (IEM) are diagnosed through mandatory newborn screening. The United States has been screening babies for PKU for over 50 years.
- Twenty-two of the 34 core conditions on the HHS Recommended Uniform Screening Panel (RUSP) must be treated with the medical nutrition for life. There is no alternative to this treatment.
- Congress has already improved coverage for military families with TRICARE: Medical Nutrition Equity Act language was included in the National Defense Authorization Act for Fiscal Year 2017 and implemented successfully in December 2017.

With early and continuous treatment, babies with PKU can grow up to be healthy, productive adults.

View and Download Advocacy Materials & Guides at:
www.npkua.org/Take-Action/Medical-Nutrition-Equity-Act

The Medical Nutrition Equity Act will save lives!