



National  
**PKU**  
Alliance

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## Statement of Support for Healthcare for Individuals with Phenylketonuria (PKU)

The National PKU Alliance (NPKUA) works to improve the lives of individuals with PKU, a rare inherited metabolic disorder diagnosed through newborn screening. PKU results in severe disability if left untreated.

The United States has screened newborns for PKU for over half a century. Our mandatory newborn screening system carries with it a responsibility for comprehensive long-term follow-up and treatment. Today, the Affordable Care Act provisions eliminating denials for pre-existing conditions, prohibiting annual or lifetime coverage limits, providing insurance for young adults up to age 26, and expanding access to Medicaid are helping children and adults with PKU stay healthy.

The NPKUA hopes any future healthcare legislation will retain these important provisions, as well as incorporate coverage of medical foods, the cornerstone of PKU treatment. The experience of PKU patients continues to demonstrate that insurance without coverage of medically necessary and efficacious treatments – including in our federal health programs – continues to have a detrimental impact on patients, their families, and society.

After more than 50 years of screening, far too many individuals with PKU struggle to gain access to the lifelong treatment they need. 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. In addition, an untreated PKU patient can no longer contribute to society as a wage earner and taxpayer. Instead, they become dependent upon government programs such as disability and Medicaid.

Health policy protecting the health of children and adults with PKU and other newborn screening conditions should be a national priority. The NPKUA respectfully asks the President and Congress to maintain key provisions of the Affordable Care Act, and resolve coverage issues related to medical foods for inherited metabolic disorders.

### References:

[American Medical Association Resolution - Health Coverage for Nutritional Products for Inborn Errors of Metabolism \(Inherited Metabolic Disorders\)](#)

[Genetic Metabolic Dieticians International Position Statement on Medical Foods](#)

[Senate Resolution 627 Designating December 3, 2016 as National Phenylketonuria Awareness Day](#)

[Summary of Medical and Dietary Guidelines for the Treatment of PKU](#)

[Full Medical Guidelines for the Treatment of PKU](#)