



National
PKU
Alliance

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MEDICAL FOODS FOR TREATMENT OF INBORN ERRORS OF METABOLISM DIAGNOSED THROUGH NEWBORN SCREENING

Every baby born in the United States is screened for the early identification of inborn errors of metabolism as a public health activity to prevent severe disability and death. The Affordable Care Act now guarantees that the uniform newborn screening panel is fully covered by insurance plans. This coverage requirement implies a social responsibility for comprehensive long-term follow-up and treatment for these conditions.

We are asking that the essential treatments needed to prevent disability in PKU and other inborn errors of metabolism diagnosed through newborn screening be included as a covered benefit as the Department of Health and Human Services proposes and adopts regulations related to the implementation of the Affordable Care Act. These essential treatments include medical foods, foods to be modified as low protein, supplements and amino acids.

- Medical evidence has demonstrated the safety and efficacy of medical foods as treatment for inborn errors for more than 50 years. Just recently, the National Institute of Health reaffirmed the necessity of medical foods treatment for PKU across the lifespan in the 2012 Scientific Review Conference on Phenylketonuria.
- Treatments for inborn errors are currently covered in 38 states through a state insurance mandate or state program. Failure to include coverage at the federal level is disastrous and expensive.
- The long-term costs associated with caring for untreated children and adults far exceeds the cost of providing this essential health benefit.
- The failure to include coverage for medical foods discriminates against individuals with PKU and similar inborn errors based on their disability, which is expressly prohibited by the Affordable Care Act.

Decades ago, before the implementation of newborn screening and treatment with medical foods, children and adults with PKU were doomed to a life of mental retardation and costly institutionalization. Now, because of mandatory newborn screening and the proven treatment with the medical foods, children and adults with PKU can lead normal and health lives. Don't put these lives at risk.