

November 30, 2011

The Honorable Kathleen Sebelius
Secretary of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Sebelius:

The undersigned organizations are writing to ask you to include the coverage of medical foods and other foods modified to be low in protein for the treatment of a number of disorders identified through newborn screening as part of the essential health benefit package under the Affordable Care Act in the chronic disease management category.

As you are aware, every child in the country is screened for the early identification of inborn errors of metabolism as a public health activity. Newborn screening is covered under the Affordable Care Act, and so it is justified that the treatment needed for these inborn errors should also be covered. These essential treatments include medical foods, foods to be modified as low protein, supplements and amino acids.

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 would be disastrous and expensive. If these disorders are not diagnosed and treated at birth and throughout the life span, the result is serious disability or death. The long-term costs associated with caring for untreated children and adults far exceeds the cost of providing this essential health benefit. In addition, not covering treatment will lead to discrimination based on disability.

At HHS's request, the Institute of Medicine proposed a set of criteria and methods to be used in determining what benefits are most important for coverage under the Affordable Care Act. As it relates to specific treatments, the IOM suggested that the treatment in question must (i) be safe; (ii) be medically effective and supported by a sufficient evidence base; (iii) demonstrate meaningful improvement in outcomes over other services/treatments; (iv) be a medical service (not a social or educational one); and (v) be cost effective. Medical foods for the treatment of inborn errors of metabolism meet all of these criteria.

We urge you to include treatment for inborn errors in the essential health benefit package as recommended by the Secretary's Advisory Council on Heritable Disorders in Newborns and Children. Covering the treatment needed for these inborn errors means that children diagnosed with these disorders will be able to grow up healthy and become productive citizens. These children and adults need equitable access to life sustaining treatment just like patients with diabetes or heart disease.

We ask that you make the right decision.