

The Medical Nutrition Equity Act

Background

Specialized foods are medically necessary for the safe and effective management of digestive and inherited metabolic disorders that impact digestion, absorption, and metabolism of nutrients. For example:

- People with the inherited metabolic disorder called phenylketonuria (PKU) cannot utilize the amino acid, phenylalanine, so must consume a phenylalanine-free liquid medical formula every day for life.
- Infants with the digestive condition called short bowel syndrome often cannot absorb protein unless it is broken down into its component amino acids, provided as a specialized nutritional formula.
- Children and adults with cystic fibrosis often require high calorie tube feedings to help maintain their weight and lung function.
- Many patients with digestive and metabolic disorders also require supplementation of specific vitamins to avoid deficiencies.

Without these specialized foods, infants, children, and adults can suffer adverse health consequences, including hospitalization, intellectual impairment, behavioral dysfunction, inadequate growth, nutrient deficiencies, and even death.

Although these foods are essential for patients, they are often expensive and not uniformly reimbursed by health insurance, leaving many families with a large financial burden.

Legislation

The **Medical Nutrition Equity Act** would provide public and private insurance coverage for *medically necessary foods*¹ (including vitamins) for digestive and inherited metabolic disorders.

- **Digestive conditions include:** inflammatory bowel disease (e.g. Crohn's disease and ulcerative colitis), eosinophilic digestive disorders, food protein induced enterocolitis syndrome (FPIES), IgE mediated food allergies, and malabsorption due to liver or pancreatic dysfunction or short bowel syndrome.
- **Inherited metabolic disorders include:** metabolic disorders on the Recommended Uniform Screening Panel Core Conditions list of the Secretary of Health and Human Services' Advisory Committee on Heritable Disorders in Newborns and Children; and other genetic metabolic disorders requiring special foods.

Medically necessary foods would be covered under Medicaid, CHIP, Medicare, TriCare, FEHBP, and private insurance if they are prescribed by the patient's provider.

The Medical Nutrition Equity Act would ensure that public and private insurance covers medically necessary foods required to prevent severe disabilities and death so that children and adults with digestive and inherited metabolic disorders can become healthy and productive citizens.

The Impact of PKU

About 15,000 people in the United States have PKU, while 5,000 have another type of inborn error of metabolism.

*The average annual cost of **medically necessary food** for PKU is approximately **\$20 per day**.*

*However, care for an untreated PKU patient in **residential treatment** costs at least **\$165 per day**.*

The Impact of Crohn's Disease

An estimated 780,000 people in the United States have Crohn's disease.

*The cost to provide **medically necessary food** to induce remission is only about **\$10 per day**.*

*However, the cost to provide **drug therapy** to induce remission may cost as much as **\$80 per day**.*

¹ The terminology *medically necessary foods* is being used instead of *medical foods* to avoid confusion with the Orphan Drug Act (ODA) definition of medical foods. The ODA definition, which requires a product to be *specifically designed* to meet the *distinctive nutritional requirements* of a patient, is overly narrow in relation to how nutritional products are currently developed and used in the health care setting.