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 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 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.

The **Medical Nutrition Equity Act** would provide public and private insurance coverage for medically necessary foods (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, FEHB, 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.

For more information or to become an cosponsor, contact: Sara Mabry ([sara.mabry@casey.senate.gov](mailto:sara.mabry@casey.senate.gov)) with Sen. Casey, Karen Summar ([karen.summar@grassley.senate.gov](mailto:karen.summar@grassley.senate.gov)) with Sen. Grassley, Michele Viterise ([michele.viterise@mail.house.gov](mailto:michele.viterise@mail.house.gov)) with Rep. Delaney, Jessica Wixson ([Jessica.wixson@mail.house.gov](mailto:Jessica.wixson@mail.house.gov)) with Rep. Herrera Beutler

The Medical Nutrition Equity Act will save and improve lives!
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.

The American Medical Association recently passed a resolution in support of legislation requiring insurance coverage for specialized medical food products used to treat 28 inborn errors of metabolism, including PKU.

Even though PKU has been identified through newborn screening for over 50 years, health insurance coverage for treatment varies across the United States and continues to have a detrimental impact on individuals with PKU, their families, and society.