

United States Senate

WASHINGTON, DC 20510

September 15, 2021

Dear Colleague:

We recently reintroduced the *Medical Nutrition Equity Act* (S. 2013/H.R. 3783). This legislation, which has bipartisan support, is vital to children and adults living with digestive or inherited metabolic disorders that prevent their bodies from digesting or metabolizing food. When these conditions are left untreated, food can become toxic or the body can fail to absorb necessary nutrients. These individuals must turn to medically necessary nutrition, such as highly specialized formulas, both as a treatment for their condition and as sustenance.

An example of one of these conditions is Phenylketonuria (PKU)—a metabolic disorder that requires vigilant management of daily macronutrients. Typically, the amount of protein a person with PKU can consume per day cannot exceed the amount in one egg. While PKU patients can supplement with fruits and vegetables which are low in protein, they can't meet their caloric needs through these foods alone. Most manage these complex nutritional needs by consuming specialized formulas, because failure to maintain the required diet puts them at risk for brain damage, repeated hospitalizations, failure to grow or even death. In other words, their condition cannot be managed by just avoiding certain foods. Specialized medically necessary nutrition prescribed by a health care provider is standard-of-care treatment for these patients and is essential to healthy development.

The *Medical Nutrition Equity Act* would require insurance coverage for these specialized formulas for patients with specific diseases and disorders of the gastrointestinal system and inherited metabolic disorders. It is narrowly drafted to focus on individuals for whom this medically necessary nutrition is the *treatment* for their diseases.

For some of the covered disorders, the legislation simply establishes treatment parity. For example, medically necessary nutrition is routinely denied by insurance companies for the management of Crohn's disease, while more costly and more risky treatments are approved. When an insurance company does cover a medically necessary formula, it typically comes with the stipulation that the formula be administered through a surgically placed tube, even if the patient is able to consume the formula by mouth. These types of coverage policies are not rational, are not cost-effective and interfere with medical decision making.

Nearly 40 states require coverage of medically necessary nutrition, but coverage is highly variable from state to state and does not apply to private sector health plans covered by the Employee Retirement Income Security Act (ERISA). Approximately 2,000 infants every year are diagnosed with an inherited metabolic disorder, because all states have mandated testing for these disorders. Yet treatment of these disorders goes uncovered for far too many.

There is precedent for this legislation. In December 2016, as part of the Defense Authorization Act, Congress required improved coverage for medical nutrition for military families enrolled in TRICARE. Our bill expands coverage to include patients covered under Medicaid, the

Children's Health Insurance Program (CHIP), Medicare, the Federal Employee Health Benefit Program, and private insurance.

Two of the stories we have heard from our own constituents are below to help you understand what is at stake when medically necessary nutrition is not accessible. To read stories from your state, please visit nutritionequity.org/states.

Ellie – newborn from Pennsylvania diagnosed with Homocystinuria (HCU)

Ellie was diagnosed as a newborn with Homocystinuria, a rare inherited metabolic disorder that prevents the body from processing the amino acids in protein. While most mothers who have a two week old are just making sure they are producing enough milk or getting enough formula, Ellie's family was in the NICU being told their daughter would have to follow a specific, low protein diet for the rest of her life. They were in the NICU for 6 days. While there, they researched the disease, the food they would have to get, and the consequences of not following the diet: lens detachment, back surgery in her teens, and stroke to name a few of the scary things their newborn may face. Ellie's mother thought, "this isn't her fault; it's not fair" over and over and still thinks it daily, months later.

Ellie's diet includes Holminex, a highly specialized formula that gives her the nutrients to survive without the harmful amino acid that her body cannot process. Ellie is at an age at which she is starting to try solid foods and so her family has to get special foods for her that are low in protein. They are very expensive. In addition to spending \$60 per can for her formula, it costs \$16 per loaf for the special low protein bread that she can eat.

Mason – 2 year old from Iowa diagnosed with PKU

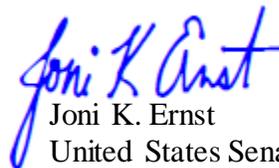
Mason's family had never heard of PKU until their son was diagnosed through the newborn screening program. They are so grateful for the early detection that will allow Mason to live a healthy life. Although screening for PKU is mandatory, treatment is often not covered by insurance. In order to prevent permanent brain damage, Mason will have to follow a strict low protein diet, avoiding meat, dairy, eggs, nuts, and other high protein foods. In order to do this, his family relies heavily on specially engineered medical food and a medical formula to replace the nutrients he misses through his strict diet. Mason's medical formula is covered after his family meets an \$8,000 deductible, but they pay 100 percent until then and his medical food is not covered at all. The medical food and formula is the only thing keeping Mason from irreversible brain damage.

If you have questions or wish to cosponsor the legislation, please contact Kate Samuelson in Sen. Casey's office at Kate_Samuelson@help.senate.gov or Konner Fowler in Sen. Ernst's office at Konner_fowler@ernst.senate.gov.



Robert P. Casey, Jr.
United States Senator

Sincerely,



Joni K. Ernst
United States Senator