



The Medical Nutrition Equity Act (S. 2013/ H.R. 3783): *Providing a Cost-Effective Lifeline to Americans with Rare Digestive and Metabolic Diseases*

Thousands of children and adults in our country live with digestive (i.e. gastrointestinal, liver or pancreatic disease) or inherited metabolic disorders that inhibit their bodies from digesting or metabolizing typical grocery store foods. 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, as a treatment for their condition and as sustenance.

Without medically necessary nutrition, risks can include unnecessary surgery and repeated hospitalizations, intellectual disability or even death. Risks in pediatric populations are particularly profound and when medically necessary nutrition is delayed or cannot be obtained the result is often severe: inadequate growth, abnormal development, cognitive impairment, behavioral disorders, in addition to those mentioned above. Specialized medical nutrition is standard-of-care therapy for these patients and is necessary to prevent such horrible outcomes.

Medically necessary nutrition typically must be ordered through a pharmacy and costs 4-5 times the cost of “normal” food. While this cost puts significant strain on families in the best of times, the cost burden has worsened for many throughout the COVID-19 pandemic.

Insurance Companies Do Not Generally Cover Medically Necessary Nutrition

- Insurance companies will typically cover pharmaceuticals or biologics for treatment of a digestive or metabolic condition. However, these types of treatments are often used off-label or may not be recommended by the treating physician as first-line therapy.
- Pharmaceuticals and biologics are often costly and can have undesirable risks such as suppression of the immune system, which can increase a patient’s risk of infection and certain cancers. Patient exposure to these risks can be compounded because many of these treatments begin in childhood and must be continued long-term, even for life.
- Even when an insurance company does cover medical nutrition, it often comes with the arbitrary stipulation the formula be administered through a nasogastric tube (a tube placed in the nose and into the stomach) or through a gastrostomy tube (a surgically placed tube directly in the patient’s stomach), which is expensive and carries additional risks. For example, a gastrostomy tube can leak, cause ulcerations, or a patient may experience infection at the insertion site. In severe cases, some patients with feeding tubes experience a perforation in the intestinal tract.
- In contrast, specialized formulas, when administered under a physician’s order, are life-saving treatments with lower costs and fewer risks.

States Have Passed a Variety of Laws, but Too Many Patients Fall Through the Cracks

Most states have implemented some level of protection for patients who rely on medical nutrition in state-run programs or state-regulated private insurance. The fact so many states have passed legislation on this issue demonstrates its importance. Unfortunately, state laws vary considerably. Further, the majority of Americans get their health coverage through federally regulated insurance plans or pro-

grams. As a result, many patients still face obstacles when trying to access medically necessary nutrition, even in states that have passed comprehensive laws. Consider the following scenarios that underscore the current patchwork of coverage policies fail far too many patients:

- A patient with phenylketonuria (PKU) lives in a state with a medical nutrition coverage law but is covered by their employer's plan based in another state without a law. This patient would have no coverage for his metabolic formula, which he needs to survive.
- Even with a state law, a federal employee who is covered by a federal Blue Cross/Blue Shield plan that does not cover medical foods will be unable to access her needed formula unless the patient is tube-fed or the medical food is the sole source of nutrition.
- Many states' Medicaid programs do not cover low-protein foods.
- Finally, while all states have mandated testing for select inborn errors of metabolism, and approximately 2,000 babies per year are diagnosed with an inherited metabolic disorder as a result, state medical nutrition coverage policies for these conditions vary widely.

The Medical Nutrition Equity Act Would Close the Gaps

- The *Medical Nutrition Equity Act* (S. 2013/ H.R. 3783) would ensure both public and private insurance cover medically necessary foods as a treatment option, which are required to support proper growth and development and to prevent medical complications, severe disabilities and death.
- The legislation is narrowly drafted to ensure it only covers patients for whom the physician-prescribed or ordered medically necessary nutrition constitutes the treatment.

There is Precedent for this Legislation: *Congress Improved Coverage for Military Families in TRICARE*

- In December 2016, Congress passed legislation that improved coverage for medical nutrition for military families enrolled in TRICARE.
- Prior to the passage of the new statute, TRICARE medical nutrition coverage policies were inconsistently applied and fell short of meeting the needs of TRICARE beneficiaries.

But TRICARE Coverage Was Just the First Step:

- The *Medical Nutrition Equity Act* would build upon that success by expanding coverage to include patients covered under Medicaid, the Children's Health Insurance Program (CHIP), Medicare, the Federal Employee Health Benefit Program, and private insurance.
- Recognizing the importance of understanding the costs of implementing this legislation, the PPMNE Coalition commissioned an independent firm to complete a cost analysis of the legislation. Their conservative cost estimate was \$132 million per year to improve access to medically necessary nutrition for this vulnerable patient population. The bill champions have also requested a Congressional Budget Office cost estimate.

YOU Have the Power to Provide a Lifeline to Your Constituents with Rare Digestive and Metabolic Conditions.

Please contact the offices of Senator Casey, Senator Ernst, Representative McGovern or Representative Herrera Beutler to co-sponsor the *Medical Nutrition Equity Act* (S. 2013/ H.R. 3783) TODAY.

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