



Increasing Access to Medical Nutrition for Rare Digestive and Metabolic Disease: Life-Saving and Cost-Effective

Co-sponsor the Medical Nutrition Equity Act (S. 1194/H.R. 2587)

Every day across this country, parents of children with certain metabolic or gastrointestinal conditions are facing brutal realities. They find that their newborn baby has a life-threatening condition and can't consume breast milk or standard formulas. Or they are worrying about how their child will consume enough nutrients to achieve sufficient growth before life-saving surgery is possible. Or they may be telling their four-year-old that he has a condition that will require him to give up solid food – forever.

Now, consider that the cost for this medically necessary nutrition is 4-5 times the cost of “normal” food. And then imagine how devastating it is to find out that it is not covered by health insurance.

Each year, thousands of children and adults in our country are diagnosed with digestive or inherited metabolic disorders that prevent their bodies from digesting or metabolizing the food they need to survive. When these conditions are left untreated, food can become toxic or the body can fail to absorb necessary nutrients.

Without medical nutrition, the risks can include surgery, hospitalization, intellectual disability or even death. Risks in pediatric populations are particularly profound and 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 outcomes.

Unfortunately, Insurance Companies Do Not Generally Cover Medical Nutrition

- Insurance companies will typically cover pharmaceuticals or biologics for treatment of a digestive or metabolic condition. However, these types of treatments are often not indicated for specific patients and/or conditions or may not be recommended as a first-line therapy.
- Pharmaceuticals and biologics are often costly and can have undesirable risks such as cancer or suppression of the immune system, which can increase a patient's risk of infection. Patient exposure to these risks can also be compounded due to the fact many of these treatments must be continued long-term, even for life.
- Even when an insurance company does cover medical nutrition, it often comes with the arbitrary stipulation that 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.

Thirty-five States Have Passed Laws, but Too Many Patients Fall Through the Cracks

The fact that so many states have passed legislation on this issue demonstrates its importance. Unfortunately, even patients who live in states with coverage laws still face many obstacles and continue to be denied the coverage and assistance they require. Consider the following scenarios that underscore that our current patchwork of coverage policies fail far too many patients:

- A patient with phenylketonuria (PKU) lives in a state that has a coverage law in place, but is covered by their employer's plan based in another state without a law in place. This patient would have no coverage for his metabolic formula, which he needs to survive.
- Even with a state law in place, a resident 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 more than 7,000 babies per year are diagnosed with an inherited metabolic disorder as a result, state medical nutrition coverage policies for these conditions vary widely.

There is an Additional 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* (S.1194/H.R.2587) would build upon that success by further 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.
- The *Medical Nutrition Equity Act* would ensure that both public and private insurance cover medically necessary foods, which are required to prevent severe disabilities and death.
- The legislation is narrowly drafted to ensure that it only covers patients for whom the physician-prescribed medical nutrition constitutes the treatment.

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

Please contact the offices of Senator Grassley, Senator Casey, Representative Herrera Beutler or Representative Delaney to co-sponsor the Medical Nutrition Equity Act (S. 1194/H.R. 2587) TODAY.

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