

9/22/2022

Dear Colleague,

Over the last few months, we've all heard devastating stories from our constituents about the formula shortage. We are encouraged by USDA's efforts, including the extension of infant formula waivers to increase accessibility for families, but many people are still struggling to get the food they need for their children and themselves. The formula shortage has affected healthy infants, but also infants, children, and even adults who rely on specialty formulas to treat certain inherited metabolic diseases or gastrointestinal conditions that prevent their bodies from digesting or metabolizing regular foods. When these conditions are left untreated, the body can fail to absorb necessary nutrients and food can even become toxic. It's not uncommon for a person to be hospitalized due to their inability to access these specialty formulas.

Unfortunately, many of the infants, children, and adults who rely on specialty formulas to survive still face coverage and cost barriers. We invite you to join the bipartisan *Medical Nutrition Equity Act* to remove these barriers.

The *Medical Nutrition Equity Act* would require coverage of these specialized formulas for patients with specific gastrointestinal and inherited metabolic diseases and disorders. It is narrowly drafted to focus on individuals for whom 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 treatments that put children at risk of medical complications are approved. As the formula shortage has demonstrated, specialty formulas are not a luxury for the individuals who rely on them; they are necessary. When a health insurance company does cover a medically necessary formula, it can currently come with the stipulation the formula be administered through a surgically placed tube. These types of coverage policies are not rational, are not cost-effective and interfere 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 patients covered by private sector health plans governed 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, Congress passed as part of the National Defense Authorization Act 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.

If you would like more information, we are happy to send you stories from your state. Please contact Bella Edo in Rep. McGovern's office at Bella.Edo@mail.house.gov or Adrianna Lagorio in Rep. Herrera Beutler's office at Adrianna.Lagorio@mail.house.gov if you have questions or wish to cosponsor this legislation.