



November 14, 2022

The Honorable Chuck Schumer  
Majority Leader  
U.S. Senate  
Washington, DC 205105

The Honorable Mitch McConnell  
Minority Leader  
U.S. Senate  
Washington, DC 20510

Dear Majority Leader Schumer and Minority Leader McConnell:

The Patients & Providers for Medical Nutrition Equity, a national coalition of 45 patient and provider organizations that represent individuals for whom specialized nutrition is medically necessary for treatment of their digestive or inherited metabolic disorder, write to **request that the bi-partisan *Medical Nutrition Equity Act (MNEA, S. 2013/H.R. 3783)* is included in any end-of-year legislative package.**

The *MNEA* was introduced by Sens. Casey and Ernst and has strong bi-partisan support. It would ensure Americans with certain inherited metabolic conditions and gastrointestinal (GI) disorders have coverage through their insurance of essential treatments in the form of medically necessary nutrition, such as highly specialized formulas, for their diseases. The recent formula shortage highlighted the necessity of these formulas for the children and adults who rely on them for both treatment and sustenance. These formulas are not discretionary for patients with GI and metabolic disorders; they are a necessity. We encourage you to visit [nutritionequity.org/states](https://nutritionequity.org/states) to read stories about the need for this legislation.

The importance of improving access to medically necessary nutrition for patients with GI and metabolic disorders was included in the White House's recently released National Strategy on Hunger, Nutrition and Health. Congress has also recognized the importance of improving coverage of medically necessary nutrition by including language similar to the *MNEA* in the 2016 *National Defense Authorization Act* for TRICARE beneficiaries. The out-of-pocket costs for specialized formulas and foods to treat GI and metabolic disorders can reach thousands of dollars per month, and, for many patients and families, cost is a barrier to access and treatment. It is time to extend coverage to other insured populations and to ensure that there is a federal coverage floor.

For nearly a decade, members of the Coalition have fought tirelessly to improve access and coverage of medically necessary formulas and foods for patients with GI and metabolic disorders. We respectfully request your support for final action on the *MNEA* this year which will provide relief to the patients and families who struggle with out-of-pocket costs for their treatment.

Thank you in advance for your consideration of our request. Please contact Megan Gordon Don at 202.246.8095 or [mgdon@mgdstrategies.com](mailto:mgdon@mgdstrategies.com) if you have any questions or need more information.

Sincerely,

[The Patients for Medical Nutrition Equity Coalition](https://nutritionequity.org)