October 26, 2022

The Honorable Patty Murray
Chair
Health, Education, Labor & Pensions Committee
U.S. Senate
Washington, DC 20510

The Honorable Richard Burr
Ranking Member
Health, Education, Labor & Pensions Committee
U.S. Senate
Washington, DC 20510

Dear Chairwoman Murray and Ranking Member Burr:

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 consideration of the Medical Nutrition Equity Act (MNEA, S. 2013/H.R. 3783) by the Health, Education, Labor & Pensions Committee, with the goal of final passage before the end of the year.

The MNEA 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 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 patients. 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.

The undersigned members of the coalition ask you to act on this legislation so it can be enacted this year. Please contact Megan Gordon Don at 202.246.8095 or mgdon@mgdstrategies.com if you have any questions or need more information.

Sincerely,

The Patients for Medical Nutrition Equity Coalition

nutritionequity.org
October 27, 2022

The Honorable Frank Pallone
Chair
Energy & Commerce Committee
U.S. House of Representatives
Washington, DC 20515

The Honorable Cathy McMorris Rodgers
Ranking Member
Energy & Commerce Committee
U.S. House of Representatives
Washington, DC 20515

The Honorable Anna Eshoo
Chair
Energy & Commerce Committee, Subcommittee on Health
U.S. House of Representatives
Washington, DC 20515

The Honorable Brett Guthrie
Ranking Member
Energy & Commerce Committee, Subcommittee on Health
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Pallone, Ranking Member McMorris Rodgers, Chairwoman Eshoo, and Raking Member Guthrie:

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