PATIENTS &
PROVIDERS FOR
MEDICAL
NUTRITION
EQUITY

February 26, 2024

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

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

Dear Chair Guthrie and Ranking Member Eshoo:

The Patients & Providers for Medical Nutrition Equity (PPMNE), a national coalition of 45 patient and provider organizations that represent individuals for whom specialized nutrition is medically necessary for treatment of their gastrointestinal (GI) or inherited metabolic disease or disorder, write with support of the Committee's February 29 hearing "Legislative Proposals to Support Patients with Rare Diseases." While the *Medical Nutrition Equity Act (H.R. 6892)* is regrettably not included among the bills subject to the hearing, it is legislation strongly supported by the rare disease community. Specifically, H.R. 6892 ensures that patients with GI or inherited metabolic disorders have access to medically necessary nutrition, which includes specialized foods and formulas, to treat their diseases and disorders.

H.R. 6892 builds on the coverage of medically necessary nutrition Congress passed for TRICARE beneficiaries by extending coverage to other payors.

While the legislation has just been re-introduced this Congress by Representatives McGovern and Rutherford, our community has been advocating for passage of some version of it for over a decade and it secured significant bi-partisan support in the 117th Congress. Nearly all GI and metabolic diseases or conditions included in the *Medical Nutrition Equity Act* are considered rare diseases. Therefore, we hope you will consider H.R. 6892 for future Committee action this Congress.

The 2022 formula shortage highlighted the necessity of specialized formulas for the children and adults who rely on them for both treatment and sustenance. These formulas are not discretionary for patients with these disorders; they are essential to their medical management and survival. We encourage you to visit nutritionequity.org/category/states to read stories from individuals in your states and from across the country which underscore why passage of this legislation is imperative.

The importance of improving access to medically necessary nutrition for patients with GI and metabolic disorders was included in the White House's 2023 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.

Many members of our community are attending Rare Disease Week on Capitol Hill today. We ask that this letter and the attached fact sheet be submitted for the hearing record. We look forward to working with you to advance H.R. 6892 this Congress. Please contact Megan Gordon Don at 202.246.8095 or mgdon@mgdstrategies.com with questions or requests for additional information.

Sincerely,

Patients & Providers for Medical Nutrition Equity Coalition