

Statement on the Introduction of the Medical Nutrition Equity Act

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June 10, 2021, Washington, DC — <u>Patients and Providers for Medical Nutrition Equity</u> (PPMNE), a national coalition of more than 40 provider and patient organizations, applauds the bipartisan and bicameral re-introduction of the *Medical Nutrition Equity Act of 2021*.

Thousands of children and adults in the United States have a diagnosis of a digestive or inherited metabolic disorder that prevents their bodies from digesting or metabolizing food. Medically necessary nutrition is their condition's treatment. Too often, insurance companies deny these patients access to medical nutrition for the treatment and management of their diseases putting them at risk of medical complications. Specialized medically necessary nutrition is their standard-of-care therapy.

Medically necessary nutrition is routinely denied by insurance companies, while more costly treatments are approved. When an insurance company does cover a medically necessary formula, it typically comes with the stipulation that the formula be administered through a nasogastric or gastrostomy tube.

"Medically necessary nutrition is a risk-free, cost-effective treatment pathway for pediatric patients with disorders of the gastrointestinal system and sometimes the only mechanism for ensuring these children can achieve disease remission and necessary nutrition requirements for optimal growth and development," said Ben Gold, MD, President of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. "Medically necessary nutrition is, by definition, medically necessary and insurance policies need to reflect that.

Many states require coverage of medical nutrition, but coverage is highly variable. The *Medical Nutrition Equity Act* would require coverage of medically necessary nutrition under Medicaid, the Children's Health Insurance Program, Medicare, the Federal Employee Health Benefit Program, and private insurance for defined gastrointestinal and metabolic disorders.

"Currently, coverage for medically necessary nutrition is dependent on your age, gender and the state in which you live. This bill would close coverage gaps and ensure any baby born in the United States and diagnosed with an inborn error of metabolism will have access to the required treatment needed to lead a heathy life," said Christine Brown, Executive Director of the National PKU Alliance.

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"For many patients living with a rare disease, medical nutrition is their only viable treatment option, and it should be covered as any other necessary treatment. Without adequate coverage, patients and their families could face difficult financial choices that could lead to worsening health outcomes if they do not have their needed medical nutrition." said Peter L. Saltonstall, President and CEO of the National Organization for Rare Disorders.

PPMNE thanks Senators Bob Casey (D-PA) and Joni Ernst (R-IA) and Representatives Jim McGovern (D-MA) and Jaime Herrera Beutler (R-WA) for their critical leadership on this important issue. Advocates across the country will participate in the #SpeakUp4MNEA advocacy campaign the week of June 14 to increase awareness about the need for passage of this legislation.

Learn more at https://nutritionequity.org

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