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National Organizations Band Together to Ensure that Congress Passes Legislation to Improve Access to Medically Necessary Nutrition

Washington, D.C., June 1, 2018 — Specialized medical nutrition is often medically necessary for the management and treatment of many digestive and inherited metabolic disorders. Unfortunately, coverage of medically necessary nutrition is routinely denied by insurance companies. In response to coverage delays and denials, the Patients and Providers for Medical Nutrition Equity Coalition launched its first public event today, uniting patients and health providers around the common goal of achieving medical nutrition coverage equity.

Nearly 100 advocates — comprised of patients and their families as well as the health care professionals who treat the conditions covered by the legislation — will be on Capitol Hill today asking lawmakers to cosponsor and pass the *Medical Nutrition Equity Act* (S.1194/ H.R. 2587). This legislation, sponsored by Senators Bob Casey (D-PA) and Chuck Grassley (R-IA) and Representatives John Delaney (D-MD) and Jamie Herrera Beutler (R-WA), would provide patients with digestive and inherited metabolic disorders coverage for medically necessary nutrition. Medical nutrition consists of specially formulated and processed products used for the dietary management of individuals who have limited or impaired capacity to ingest, digest, absorb, or metabolize ordinary nutrients or who have other special medically determined nutrient requirements that cannot be sustained by the modification of an ordinary diet.

“Medical nutrition is central to the management and treatment of many conditions of the digestive system,” said James Heubi, M.D., President of the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition. “For example, oftentimes physicians can manage Crohn’s disease with formulas that carry zero risk and side effects rather than with costly drugs or biologics. What we find most often, however, is that insurers will cover the drugs and not the formula, or medical food.”

“Medical nutrition is not a regular grocery item, yet that is how many insurance companies regard it, and, consequently, they deny coverage,” said Paul Melmeyer, Director of Federal Policy for the National Organization for Rare Disorders. “Covering medical nutrition is as necessary as covering insulin for diabetics. Without access to medical nutrition, these rare diseases are likely to worsen and lead to other medical complications or even death.”

“Medical foods have been used to treat PKU for more than 50 years. The federal government requires all babies to be screened at birth to detect PKU and other disorders, yet does not require the necessary medical foods treatment to be covered. There is a complete disconnect,” said Christine Brown,

Executive Director of the National PKU Alliance. “We cannot achieve the goals of newborn screening without also ensuring access to treatment.”

This legislation builds on a TRICARE coverage improvements enacted by the 114th Congress by further expanding coverage to those under Medicaid, the Children’s Health Insurance Program (CHIP), Medicare, the Federal Employee Health Benefit Program, and private insurance.

The Coalition is also convening a congressional briefing today to educate Congress about medical nutrition and the barriers patients with certain conditions face in accessing these life-saving treatments. The briefing, featuring patients who rely on medical nutrition as well as health care providers, will be held at noon in Rayburn House Office Building, Room 2044.

For more information about the Patients and Providers for Medical Nutrition Equity Coalition, including a full list of coalition members, please visit medicalnutritionequityfor.us.

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