



June 1, 2018

Dear Senators and Representatives:

On behalf of Patients & Providers for Medical Nutrition Equity, a coalition of patient and provider organizations that represent individuals for whom specialized nutrition is medically necessary for treatment of their digestive or inherited metabolic disorder, we write to ask that you co-sponsor the Medical Nutrition Equity Act (S. 1194/H.R. 2587).

The legislation is narrowly drafted to focus on a set of digestive or inherited metabolic disorders that prevent a patient's body from processing the food that they need to survive. For these patients, specific medical foods, formulas and vitamins are essential to the treatment of their conditions and even survival. Further, these treatments are generally the most medically appropriate, least risky, and least costly alternatives. For example, for many of the digestive diseases covered in the legislation, including Crohn's disease and eosinophilic esophagitis, medical nutrition may constitute the safest and most effective therapy available to a patient. Alternatively, medical nutrition may be the preferred medical treatment, with fewer risks and side-effects than other therapeutic options.

Additionally, more than four million newborns in the United States receive state-mandated testing for inborn errors of metabolism as recommended by the Secretary of HHS' Recommended Uniform Screening Panel. Each year, approximately 7,200 of these babies are diagnosed with inherited metabolic disorders as a result of this mandated testing. For most of these babies, such as those diagnosed with phenylketonuria (PKU), the use of medical nutrition is not merely an optional, alternative food choice, but a medical necessity.

When diseases of the digestive system or inherited metabolic disorders are left unmanaged or untreated, the medical consequences are often significant, permanent, and costly. The implications of denied or delayed access to medical nutrition in pediatric populations are particularly profound — inadequate growth, abnormal development, cognitive impairment, and behavioral disorders. In severe cases, without medical nutrition, the outcome can be surgery, hospitalizations, intellectual disability, or even death. Children with an unmanaged disease also suffer emotionally and socially.

Unfortunately, patients often find that their insurance provider considers these medical foods and other forms of medical nutrition to be "groceries." Consequently, insurance coverage is denied and patients are forced to seek alternative treatments or go without treatment altogether. Medical foods and other forms of medical nutrition are not groceries, but rather a primary treatment modality for inherited metabolic disorders and diseases of the digestive system.

Further, without coverage, medical nutrition is unaffordable for many families. For example, some children with Crohn's disease require a pre-digested formula such as Peptamen 1.5, which, at five cans per day, can cost an average of \$1,500/month. For many patients and their families, the out-of-pocket costs for specialized formulas are prohibitive, particularly when you consider that these formulas cost less than biologics that are covered for some of these

conditions. Biologic therapies are not only costly, but confer medical risks, such as suppression of the immune system which can increase a patient's risk of infection.

When an insurance company does cover a medical formula, it often comes with the stipulation that the formula be administered through the nose or through a tube surgically placed in the patient's gut, which carries additional risks. For example, a gastrostomy tube can leak, cause ulcerations, or a patient may experience infection at the insertion site. In severe cases, some patients with these feeding tubes experience a perforation in the intestinal tract.

These types of coverage policies are irrational and interfere with thoughtful medical decision making. The Medical Nutrition Equity Act would ensure coverage parity, providing patients the ability to choose the best treatment option in consultation with their physician. The Patients & Providers for Medical Nutrition Equity Coalition respectfully requests that you co-sponsor this critical legislation so patients with these conditions can survive and thrive. Please contact Megan Gordon Don at 202.246.8095 or mgdon@mgdstrategies.com if you have any questions or need more information and please contact the offices of Senators Grassley or Casey or Representatives Herrera Beutler or Delaney to co-sponsor.

Sincerely,

American Academy of Pediatrics
American College of Gastroenterology
American College of Medical Genetics and Genomics
American Gastroenterological Association
American Partnership for Eosinophilic Disorders
American Society for Parenteral and Enteral Nutrition (ASPEN)
Association for Creatine Deficiencies
Association of Pediatric Gastroenterology and Nutrition Nurses
Children's Hospital at Dartmouth
Children's Hospital Colorado
Children's Medical Nutrition Alliance
Children's MAGIC US
Children's National Health System
Crohn's & Colitis Foundation
Campaign Urging Research for Eosinophilic Disease (CURED)
EveryLife Foundation for Rare Diseases
FOD (Fatty Oxidation Disorders) Family Support Group

Genetic Metabolic Dietitians International (GMDI)
HCU Network America
International Foundation for Functional Gastrointestinal Disorders (IFFGD)
Maple Syrup Urine Disease Family Support Group
March of Dimes
National Organization for Rare Disorders (NORD)
National PKU Alliance, Inc.
National PKU News
National Urea Cycle Disorders Foundation
Nationwide Children's Hospital
Network of Tyrosinemia Advocates (NOTA)
North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN)
Oley Foundation
Organic Acidemia Association
Pediatric IBD Foundation
Propionic Acidemia Foundation
Society for Inherited Metabolic Disorders