

March 14, 2016

The Honorable Mac Thornberry
Chairman
Armed Services Committee
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Adam Smith
Ranking Member
Armed Services Committee
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Joseph Heck
Chairman
Military Personnel Subcommittee
Armed Services Committee
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Susan Davis
Ranking Member
Military Personnel Subcommittee
Armed Services Committee
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairman Thornberry, Ranking Member Smith, Chairman Heck and Ranking Member Davis:

Medical foods are often medically necessary for the safe and effective management of many digestive and inherited metabolic disorders that affect digestion, absorption, and metabolism of nutrients. Yet, coverage of medical foods is routinely denied by TRICARE. The process to appeal a denial of coverage is lengthy and the outcome is varied. The undersigned organizations ask for your support to ensure that TRICARE patients with diseases of the digestive system and inherited metabolic disorders have access to medically necessary foods and vitamins when they are a prescribed treatment.

For many diseases of the digestive system, including Crohn's disease, serious liver disease and eosinophilic esophagitis, medical foods may constitute the only route of safe and effective therapy available to a patient, or they may be the preferred medical treatment, with fewer risks and side-effects than biologic therapies. In the case of inherited metabolic disorders, such as phenylketonuria, the use of medical foods is not merely an optional, alternative food choice but a medical necessity. These disorders represent a complex group of genetic conditions in which an enzyme deficiency prevents normal metabolism.

When diseases of the digestive system or inherited metabolic disorders are left unmanaged or untreated, the medical consequences are significant, often permanent and costly. The implications of denied or delayed access to medical foods in pediatric populations are particularly profound — inadequate growth, abnormal development, cognitive impairment, and behavioral disorders. In severe cases, the outcome can be surgery, hospitalizations and even death. Children with unmanaged disease also suffer emotionally and socially.

Oftentimes, TRICARE will cover a medical food, but only if administered through a tube placed in the stomach or intestine. Feeding through devices can be associated with potential complications and can be cumbersome to the family and the patient. For example, a gastrostomy tube can leak, cause ulcerations, or in severe cases, cause a perforation in the intestinal tract.

When appealing TRICARE denials, health care providers, including physicians practicing at military hospitals and clinics, are told that TRICARE "doesn't buy groceries." Medical foods are not groceries, but are a major treatment modality for diseases of the digestive system and inherited metabolic disorders and are unaffordable to many families when coverage is denied. 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 \$1500 a month. Some formulas are less expensive for the treatment of Crohn's disease yet remain cost prohibitive for many families. Coverage of medical foods for the treatment of Crohn's disease

is particularly cost effective when considering that an alternative to medical foods is the biologic class of therapeutics. Biologic therapies are costly to the TRICARE program and also confer medical risks, such as suppression of the immune system which can increase a patient's risk of infection.

On behalf of TRICARE patients with diseases of the digestive system and with inherited metabolic disorders who rely on medical foods for the treatment and management of their diseases, we ask that you require coverage, as part of the Fiscal Year 2017 National Defense Authorization Act, of medically necessary foods, including low protein modified foods and amino acid preparation products, and vitamins when they constitute the prescribed treatment for the management of a covered disease or condition.

For questions or additional information, please contact Camille Bonta at cbonta@summithealthconsulting.com or (202) 320-3658.

Sincerely,

American Academy of Pediatrics
American College of Gastroenterology
American Gastroenterological Association
American Partnership for Eosinophilic Disorders
Association of Pediatric Gastroenterology and Nutrition Nurses
Children's Hospital Colorado
Children's Magic U.S.
Digestive Disease National Coalition
Fatty Oxidation Disorders Support Group
Genetic Metabolic Dietitians International
Genetic Alliance
Maple Syrup Urine Disease Family Support Group
National Organization for Rare Disorders
National PKU Alliance
National Urea Cycle Disorders Foundation
North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
Organic Acidemia Association
Pediatric IBD Foundation
Propionic Acidemia Foundation