

Cosponsor the Medical Nutrition Equity Act

Sending Office: Honorable James P. McGovern

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Dear Colleague,

We invite you to join the Medical Nutrition Equity Act (H.R.3783). This legislation, which had bi-partisan support, is vital to children and adults who live with digestive or inherited metabolic disorders that prevent their bodies from digesting or metabolizing food. When these conditions are left untreated, food can become toxic or the body can fail to absorb necessary nutrients. These individuals must turn to medically necessary nutrition, such as highly specialized formulas, both as a treatment for their condition and as sustenance.

An example of one of these conditions is Phenylketonuria (PKU) — a metabolic disorder that requires vigilant management of daily macronutrients. Typically, the amount of protein a person with PKU can consume per day cannot exceed the amount in one egg. While PKU patients can supplement with fruits and vegetables which are low in protein, they can't meet their caloric needs through these foods alone. Most manage these complex nutritional needs by consuming specialized formulas because failure to maintain the required diet puts them at risk for brain damage, repeated hospitalizations, failure to grow, or even death. In other words, their condition cannot be managed by just avoiding certain foods. Specialized medically necessary nutrition prescribed by a health care provider is standard-of-care treatment for these patients and is essential to healthy development.

The *Medical Nutrition Equity Act* would require coverage for these specialized formulas for patients with specific diseases and disorders of the gastrointestinal system and inherited metabolic disorders. It is narrowly drafted to focus on individuals for whom medically necessary nutrition is the treatment for their diseases.

For some of the covered disorders, the legislation simply establishes treatment parity. For example, medically necessary nutrition is routinely denied by insurance companies for the management of Crohn's disease, while more costly and more risky 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 surgically placed tube. These types of coverage policies are not rational, are not cost-effective and interfere medical decision making.

Nearly 40 states require coverage of medically necessary nutrition, but coverage is highly variable from state to state and does not apply to private sector health plans covered by the Employee Retirement Income Security Act

(ERISA). Approximately 2,000 infants every year are diagnosed with an inherited metabolic disorder because all states have mandated testing for these disorders. Yet treatment of these disorders goes uncovered for far too many.

There is precedent for this legislation –in December 2016, Congress passed as part of the Defense Authorization Act improved coverage for medical nutrition for military families enrolled in TRICARE. Our bill expands coverage to include patients covered under Medicaid, the Children’s Health Insurance Program (CHIP), Medicare, the Federal Employee Health Benefit Program, and private insurance.

Two of the stories we have heard from our own constituents are below to help you understand what is at stake when medically necessary nutrition is not accessible. To read stories from your state, please visit nutritionequity.org/states. If you have questions or wish to co-sponsor the legislation, please contact Shelby Luce in Rep. McGovern’s office at Shelby.Luce@mail.house.gov or Adrianna Lagorio in Rep. Herrera Beutler’s office at Adrianna.Lagorio@mail.house.gov.

Caleb – 11 year old from Massachusetts, living with Eosinophilic Disorders

Caleb is an 11 year-old living with Eosinophilic Esophagitis (EOE), a disease in which a type of white blood cell (eosinophil) builds up in the lining of the tube that connects your mouth to your stomach (esophagus). This buildup, which is a reaction to foods, allergens or acid reflux, can inflame or injure the esophageal tissue and cause difficulty significant difficulty swallowing. Medically necessary formula has given Caleb back his health, allowed him to continue to advance in sports and school. His family reports that not knowing if they will have enough resources financial to sustain his needs puts stress on everyone but also creates undue burden on him, a child who just needs the formula to keep his Eosinophilic Esophagitis under control. Further, while their insurance covers EOE, Caleb’s formula is sometimes denied and/or covered at varying rates from month-to-month, causing the family to spend significant time on appeals.

Jordan – 33 year old from Washington, living with PKU

Jordan was born June 17, 1985 and diagnosed with the metabolic disorder PKU at 3 weeks of age. He immediately started on a specialized PKU formula and progressed to a diet at the appropriate ages. He was doing great. At that time his family lived in Louisiana and the state provided the formula for him but not the food. They moved to Texas in 1992. Unfortunately, Texas did not cover formula and they were spending \$350 on formula alone, plus trying to find and afford low-protein food products. It was tough but they did it and Jordan was doing very well. According to his family, he was funny, sweet and smart (testing in 9th grade showed that he was at college-levels). Their family circumstances changed as Jordan approached high school and adulthood, and they were no longer able to afford Jordan’s health insurance, which made his food and formula unaffordable. Jordan had to go off-diet. His behavioral and mental health changed dramatically and he became unstable and explosive. Over time, he was no longer able to hold down a job or function in society and his mental capacity and stability continued to erode and he became paranoid. Flash forward to today...it has been over three years since his family has seen Jordan. According to his mother, “I think of my son every day. I wonder where he is. I worry that he is not safe. I worry if he is even eating. I check Google frequently to see if his name pops up in case he was found hurt or deceased. My heart is broken. I don’t think, my son, as a child, ever wanted his life to be this way.”

Sincerely,

James P. McGovern

Jamies Herrera Beutler

