



June 9, 2017

The Honorable Mitch McConnell, Majority Leader
United States Senate
S-230, The Capitol
Washington, D.C. 20510

The Honorable Chuck Schumer, Minority Leader
United States Senate
S-221, The Capitol
Washington, D.C. 20510

Re: Medical Nutrition Equity Act of 2017 (S.1194)

Dear Leaders McConnell and Schumer:

On behalf of the 30 million men, women, and children affected by one of the 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for your continuing support of the rare disease community and your leadership regarding access to life-saving medical nutrition. We are writing to you to express our support for the *Medical Nutrition Equity Act of 2017* (S.1194), sponsored by Senators Grassley and Casey.

Each year, thousands of children and adults in our country are diagnosed with digestive or inherited metabolic disorders, requiring them to pursue access to life-saving medical foods and other forms of medical nutrition. These conditions, most of which are rare, require medical nutrition just like a diabetic requires insulin, or an individual with end stage renal disease requires dialysis.

Unfortunately, this medically necessary nutrition is often very expensive (upwards of \$60 per can for medical foods for individuals with metabolic conditions), and is often not covered by insurance. Instead of recognizing medical nutrition as the medically-necessary treatments that they are, insurers often consider these treatments as elective, or purely dietary, in nature. This is simply not the case; lack of access to medical nutrition can cause irreparable mental and physical harm. Thus, families continue to struggle with the perilous balance of medical and financial devastation due to the lack of coverage of these medically necessary foods.

The 114th Congress recognized this disparity in the National Defense Authorization Act by expanding access to life-saving medical nutrition for military families in the TRICARE program. The *Medical Nutrition Equity Act* takes the next step by requiring coverage of these treatments under Medicaid, Medicare, the Federal Employee Health Benefit Program (FEHBP), and private insurance. If this legislation is enacted, families will no longer face financial ruin and mental and physical harm due to lack of access to medical nutrition.

This legislation has NORD's full support, and we look forward to working with you to ensure passage of this important legislation. If you have any questions, please do not hesitate to contact Paul Melmeyer, Director of Federal Policy, at pmelmeyer@rarediseases.org or 202-545-3828.

Sincerely,

Peter L. Saltonstall
President and CEO