



January 25, 2019

Representative Jim McGovern  
408 Cannon House Office Building  
Washington, D.C. 20515

**Re: Medical Nutrition Equity Act Sponsorship**

Dear Representative McGovern:

On behalf of the 30 million men, women, and children affected by one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes to ask you to consider supporting the rare disease community by sponsoring the *Medical Nutrition Equity Act*.

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 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 114<sup>th</sup> 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. We hope to see this legislation enacted so that families will no longer face financial ruin and mental and physical harm due to lack of access to medical nutrition.

In order for that to happen, however, we need a champion. NORD sincerely hopes that you will consider standing up for the rare disease community by sponsoring this legislation in the House of Representatives. If you have any questions, please do not hesitate to contact me at [pmelmeyer@rarediseases.org](mailto:pmelmeyer@rarediseases.org) or 202-545-3828.

Sincerely,

A handwritten signature in black ink, appearing to read 'P. Melmeyer', with a long horizontal flourish extending to the right.

Paul Melmeyer  
Director of Federal Policy