



July 11, 2022

The Honorable Joseph R. Biden, Jr.
President of the United States
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

The Honorable Kamala D. Harris
Vice President of the United States
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

Dear President Biden & Vice President Harris,

On behalf of the 25-30 million Americans affected by one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for the opportunity to provide written suggestions for the September 2022 Conference on Hunger, Nutrition, and Health. As the largest national nonprofit organization representing patients with rare diseases and their families, we ask that you include medical nutrition equity as a topic of discussion during the Conference and in the development of associated strategies to address hunger, nutrition, and health in the United States.

Medical nutrition refers to foods or formulas that are prescribed by a physician and specifically created to meet a patient's highly specialized dietary needs. Many rare disease patients require medical nutrition because their condition makes it impossible to survive on regular food or over-the-counter formula alone. For example, patients with the metabolic disorder isovaleric acidemia (IVA) lack the enzyme necessary to break down the amino acid leucine, resulting in a toxic buildup of chemicals in the blood. Since leucine is found in protein, patients with IVA must limit their protein intake to as little as one gram per kilogram per day. This can make it impossible to meet the body's demands without supplemental medical nutrition products free of leucine, not only in infancy, but throughout life. Other conditions that may require medical nutrition include complex digestive and malabsorption problems, metabolic disorders, serious allergic conditions, and intestinal malformations.

Medical nutrition products are just as important to a patient's treatment regimen as the drugs or biologics prescribed to treat other medical conditions, but insurers often do not cover these medically necessary formulas and foods. Furthermore, medical nutrition is significantly more expensive than regular food, with formula for a PKU patient costing as much as \$6,500 per month. Without insurance coverage, patients are left with no choice but to pay for their medical nutrition entirely out of pocket. This cost burden forces some patients to forgo their medical

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nutrition products and suffer serious health consequences such as seizures, developmental delay, malnutrition, and more.

The current formula shortage has highlighted the importance of formula for those who need it to meet their nutritional needs, including people of all ages who rely on medical nutrition. The rare disease community is appreciative of the measures the White House has taken to address the formula shortage but addressing the shortage alone will not mitigate the significant financial burden that patients who depend on medical nutrition regularly face. It is vital for the White House to consider these patients in any strategy aimed at addressing hunger, nutrition, and health in the United States, especially as production of metabolic formula has not yet resumed at the Abbott facility in Sturgis, Michigan and metabolic formula remains in shortage.

One step the White House can take to support the rare disease community and patients who rely on medical nutrition is backing the Medical Nutrition Equity Act (H.R. 3783/S. 2013) sponsored by Representatives Jim McGovern and Jaime Herrera Beutler and Senators Bob Casey and Joni Ernst. This bipartisan legislation would mandate private and public insurance coverage of medically necessary medical nutrition products for patients with certain medical conditions. Passing the bill would lift a huge weight off the shoulders of patients who rely on these products and improve access to appropriate nutrition for hundreds of thousands of Americans.

We look forward to working with you in pursuit of equitable access to medical nutrition products for all Americans who need them and urge you to include medical nutrition equity as part of the White House Conference on Hunger, Nutrition, and Health. For more information on this important issue, please contact Allison Herryty at the National Organization for Rare Disorders at aherryty@rarediseases.org.

Sincerely,



Heidi Ross
Vice President, Policy and Regulatory Affairs
National Organization for Rare Disorders

