
Healthcare Nutrition Council

529 14th Street, NW • Suite 750 • Washington, DC 20045

The Honorable James L. Seward
Committee on Insurance Chair, State of New York
41 South Main Street
Oneonta, NY 13820

RE: HNC Support for New York Senate Bill 7826 – Amending coverage to include supplements, vitamins, medical foods and other medications necessary to mitigate and/or treat mitochondrial disease

Dear Chairman Seward:

The Healthcare Nutrition Council (HNC), representing the manufacturers of enteral formulas and parenteral solutions, supplies, and equipment, is writing to express our strong support for New York Senate Bill 7826, which would amend the current insurance law to require prescription drug coverage for supplements and vitamins and medical foods deemed necessary to mitigate and treat the symptoms of mitochondrial disease. HNC supports the bill because it will ensure patients have access to medical foods, which are used for the treatment numerous diseases and medical conditions, such as mitochondrial disease.

Patients with these chronic diseases and medical conditions often suffer from malnutrition or other medical complications. Many of these patients' anatomy require a specifically formulated or specialized diet that is referred to as an amino acid-based or peptide-based diet. Such diets are specially designed to help them properly digest essential nutrients stay healthy, and to support growth and development in children. Additionally, decades of research shows that specialized foods are medically necessary for the safe and effective management of digestive diseases and inherited metabolic disorders that impact the digestion, absorption, and/or metabolism of nutrients. Therapeutic nutrition products, like medical foods, are critical products for individuals with a variety of underlying medical conditions who cannot maintain their nutritional health through their regular diets. Malnutrition and other complications can arise in these vulnerable patients as a result of their underlying conditions that may impair their ability to absorb nutrients from conventional foods. When patients become malnourished, they are at a significantly higher risk for negative complications, including mortality.ⁱ

Despite these potential complications and the clear benefits such specialized products provide to patients when their use is indicated, many families face significant financial burdens or lack access to medical foods when such products are not covered by their insurance provider.ⁱⁱ HNC supports the increased access to medical foods, due to the fact that these products contribute to the intervention for malnutrition and may help manage GI disorders and conditions. Additionally, infants, children and adults use these specialized formulas to reduce their risks of developing adverse health consequences, including hospitalization, inadequate growth, nutrient deficiencies, or even death. To help ensure patients with mitochondrial disease receive access and can afford the medically necessary medical foods, HNC encourages the Committee on Insurance to quickly pass the bill through Committee and to the Senate Floor for a full vote. Passage of this legislation will directly benefit these patients and their families and will also preemptively address the complications and added medical expenses associated with the management of these conditions.

Importance of Medical Foods

Interventions recommended by healthcare providers for patients with mitochondrial disease typically include some type of specialized nutritional support.ⁱⁱⁱ Medical foods are deemed necessary by many health care providers for those patients who cannot tolerate hydrolyzed protein or need an amino acid-based formula^{iv} Without medical foods, infants, children, and adults can suffer adverse health

consequences, including hospitalization, inadequate growth, nutrient deficiencies, or even death.^v Because of how they are formulated, these products require minimal digestive function to be broken down and absorbed, making it easy to digest for patients in a malabsorptive state.^{vi} Many patients rely on medical foods to help intervene with and manage chronic medical conditions, complications and comorbidities related to the poor absorption of nutrients because such nutrients would be otherwise unavailable to them through a conventional diet.

Although medical foods are essential to patients suffering from specified digestive and inherited metabolic disorders, they are often too expensive if not reimbursed by health insurance. If these infant, pediatric, and adult populations do not receive treatment for their symptoms of mitochondrial diseases with products like medical foods as a result of financial hardships of the family or lack of access, malnutrition and associated severe medical complications can occur, which can be life-threatening. Additionally, the growth and development of infants and children can be compromised.^{vii viii}

Without legislation like Senate Bill 7826, these families can be left with a huge financial burden just for providing the nutrition interventions needed to support their loved one's health. Due to the critical nutrition that medical foods provide patients, HNC believes that these products should be made available to all patients, adults and children alike, if they suffer from mitochondrial disease for which such products are clinically indicated.

Conclusion

Given the importance of medical foods for certain patient populations, HNC supports New York Senate Bill 7826 and encourages its enactment into law. We commend the New York State Legislature for recognizing the gap in insurance coverage for these important medical foods that are needed to help intervene with and manage many chronic medical conditions, complications and comorbidities.

HNC welcomes the opportunity to work with the New York Senate, relevant stakeholders, doctors, and patient groups to identify additional disease states where medical foods would be deemed clinically necessary by a health care professional. Legislation is needed to ensure that patients with varying medical conditions, like mitochondrial disease, can receive these specialized products when deemed medically necessary.

Thank you for the opportunity to comment on this bill. If you have any questions or would like additional information, please do not hesitate to reach out.

Sincerely,



Nadia Cayce, PhD
Executive Director

ⁱ White JV, Guenter P, Jensen G, Malone A, Shofield M. Consensus Statement: Academy of Nutrition and Dietetics and American Society for Parenteral and Enteral Nutrition: Characteristics Recommended for the Identification and Documentation of Adult Malnutrition (Undernutrition). *Journal of Parenteral and Enteral Nutrition*. 2012;36 (3):275-283.

ⁱⁱ Walia, C, Van Hoorn, M, Edlbeck, A, et. al.: The Registered Dietician Nutritionist's Guide to Homemade Tube Feeding. *Journal of the Academy of Nutrition and Dietetics*, 2017; 117: 1: 15-16.

ⁱⁱⁱ Id.

^{iv} Latcham et al, A consistent pattern of minor immunodeficiency and subtle enteropathy in children with multiple food allergy. *J Pediatric*. 2003.

^v Coleman MS, Kellermann A, Andersen R, et. al: Health Insurance is a Family Matter. *Insurance Health*. Institute of Medicine of the National Academies. National Academy of Sciences. 2002; 122-123.

^{vi} Id.

^{vii} Thompson JS, Rochling FA, Weserman RA, Mercer DF. Current management of short bowel syndrome. *Current Problems in Surgery*. 2012;49(2):52-115.

^{viii} Thompson JS, Rochling FA, Weserman RA, Mercer DF. Current management of short bowel syndrome. *Surgical Clinics of North America*. 2011;91(3):493-510.