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July 15, 2022

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**NASPGHAN Annual Meeting**  
**50<sup>th</sup> Anniversary**  
**October 1-17, 2022**  
**Orlando, FL**

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President Joseph Biden  
The White House  
1600 Pennsylvania Ave NW  
Washington, DC 20500

Vice President Kamala Harris  
The White House  
1600 Pennsylvania Ave NW  
Washington, DC 20500

Dear President Biden and Vice President Harris:

The North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) commends the Biden-Harris Administration for its efforts - including the highly anticipated White House Conference on Hunger, Nutrition and Health - to end hunger *and* to increase healthy eating and physical activity by 2030, so that fewer Americans experience diet-related diseases.

NASPGHAN represents more than 2,200 pediatric gastroenterologists and pediatric registered dietitian nutritionists in the United States and is the only organization singularly dedicated to advocating for children with gastrointestinal, liver and nutrition-related diseases and disorders.

Pediatric gastroenterologists are specially trained and board certified in the provision of comprehensive care for children with digestive conditions, as well as nutrition to ensure health and treat specific diseases. As pediatric specialists, NASPGHAN members regularly care for infants and children with gastrointestinal disorders related to severe protein intolerance, allergies, malabsorption, and poor growth who require specialized (non-standard) formulas to thrive. For example, up to 3-8 percent of infants born worldwide may be affected by a milk protein allergy and require either hypoallergenic, extensively hydrolyzed or amino acid-based formulas as their sole source of nutrition — the same formulas that have been in short supply since February 2022.

Although NASPGHAN recognizes the current formula shortage to be a significant crisis, we also have firm belief that through your Administration's efforts and that of others, it will be resolved. However, we also know that many children, who are our patients, were in crisis *before the shortage* because insurance companies often deny or restrict coverage of medically prescribed formulas, which are essential to ensuring patient health and have high costs. A crisis of access to specialty formulas by children who need them to grow and thrive will persist long after the shortage crisis has subsided, unless specialty formula coverage by health insurance companies is mandated.

NASPGHAN led the first introduction of the *Medical Nutrition Equity Act* (S. 2013 / H.R. 3783) in 2017 and has advocated its support for the legislation since then. The bill would require coverage of specialized formulas, as well as other medically necessary foods and specialized vitamin formulations, for patients with specific diseases and disorders of the gastrointestinal system and inherited metabolic disorders.

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 pharmacological treatments (i.e. medication) that put children at risk of medical complications, most often stemming from a suppressed immune system, are approved. As the current formula shortage has demonstrated, specialty formulas are not a luxury for the individuals who rely on them — they are a validated essential medical treatment, and, frequently, a pediatric patient's sole source of nutrition. When an insurance company does cover a medically necessary formula, it typically comes with the stipulation that requires the formula to be administered through a surgically placed tube. These types of coverage policies are not based on medical science, are not cost-effective, may create situations that put patients at risk for more harm than benefit from unnecessary procedures, and interfere with physician medical decision making and patient well-being.

Nearly 40 states require some level of coverage of medically necessary nutrition, but coverage is highly variable from state to state and does not reach patients enrolled in health plans covered by the Employee Retirement Income Security Act (ERISA).

There is precedent for coverage of medically necessary nutrition. In December 2016, Congress improved coverage for medically necessary nutrition for TRICARE beneficiaries through passage of the *National Defense Authorization Act*. The *Medical Nutrition Equity Act* extends coverage of medically necessary, or essential, nutrition to those covered under Medicaid, the Children's Health Insurance Program, Medicare, the Federal Employee Health Benefit Program, as well as those covered by private insurance.

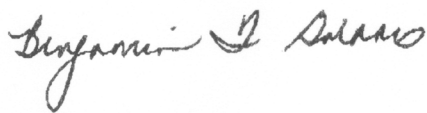
Populations that have unique food and nutritional requirements, as well as those who require specialized foods and formulas to prevent, mitigate or treat disease, are all vulnerable, as the formula shortage has highlighted. Additionally, when parents and caregivers strain to cover the cost of specialized foods and formulas for a child with a GI or metabolic disorder, the entire family is at risk of hunger when budgets are exhausted and grocery bills become unaffordable. This is unacceptable and policy solutions are long overdue.

Among the five pillars that define the scope of the White House Conference on Hunger, Nutrition, and Health, the one that resonates most strongly with those who rely on medically necessary food, as well as their treating physicians, is "Improve Food Access and Affordability." NASPGHAN asks that when using this pillar to identify actions that can be taken to end hunger by making it easier for everyone to access and afford food, those with GI and metabolic disorders should not be forgotten and support for the policies laid out in the *Medical Nutrition Equity Act* be accepted as a key solution Congress and the Federal Government can take.

NASPGHAN appreciates this opportunity to provide this input as you and members of your Administration develop an enduring national strategy to end hunger and reduce diet-related diseases and the disparities surrounding them. We would be honored to participate in the conference and lend the expertise of our members to discussions pertaining to medically necessary nutrition and in all aspects of childhood nutrition-related diseases and disorders.

For additional information, please contact Camille Bonta, NASPGHAN policy advisor, at (202) 320-3658 or [cbonta@summithealthconsulting.com](mailto:cbonta@summithealthconsulting.com).

Sincerely,



Benjamin D Gold MD, FAAP, FACP, NASPGHAN-F  
President

North American Society for Pediatric Gastroenterology, Hepatology and Nutrition