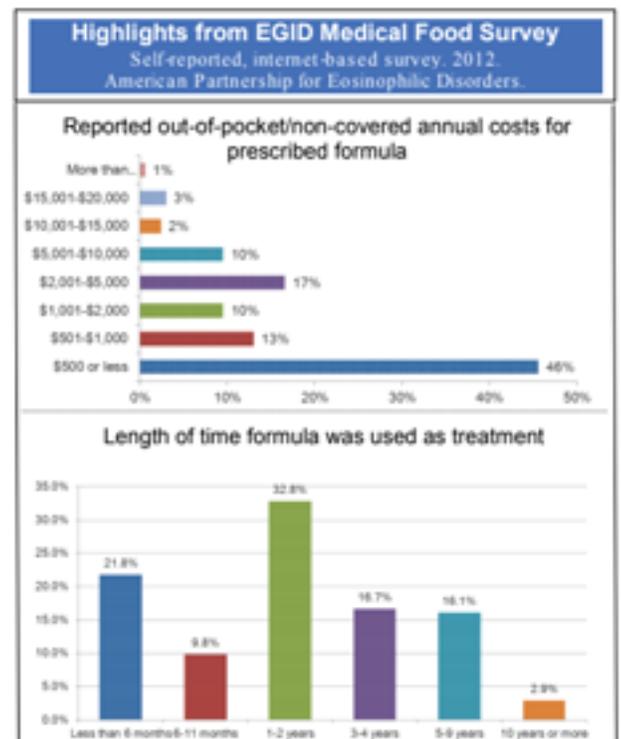


HOW COVERAGE OF MEDICAL FOODS CAN SAVE LIVES & COSTS

EOSINOPHIL-ASSOCIATED GASTROINTESTINAL DISEASE

Eosinophil-associated gastrointestinal disease such as eosinophilic esophagitis, gastritis, gastroenteritis and colitis (collectively known as “EGIDs”) are a chronic and complex group of diseases characterized by having above normal amounts of eosinophils, a type of white blood cell, in one or more specific locations in the digestive system. Accumulation of these cells cause inflammation and damage to the surrounding tissues and organs. While symptoms may vary among EGID subsets, common shared symptoms include abdominal pain, diarrhea, fatigue, nausea, poor growth, bloating, and vomiting. Patients may also have difficulty with feeding, tolerating foods, and/or gaining weight. EGIDs affect more than 52 per 100,000 individuals in the United States. There are no FDA approved therapies for EGIDs. Treatment goals include reducing the number of eosinophils and the associated symptoms, inflammation, and damage. **Two main therapies include:**

- 1. Dietary Therapy:** Food allergies may have a possible role in EGIDs, therefore patients may be prescribed elimination diets (avoiding specific foods or food groups) and/or specialized amino-acid-based formulas (elemental/“medical food”)
- 2. Medications:** Medications such as systemic or topical steroids may be prescribed “off-label.” For many patients with EGID, proper nutritional therapy is critical to achieving good health, and may in some instances be more important than prescription medications. Elemental formulas are designed to provide complete nutritional support for patients. For some patients, formula therapy is the sole treatment, and for others, these formulas provide the major source of nutrition because of suboptimal caloric intake due to a severely restricted diet. Studies have demonstrated that elemental formulas are highly effective in successfully treating patients with eosinophilic esophagitis.



Unfortunately, many commercial insurance carriers do not reimburse costs associated with amino acid-based formula to treat EGID. As a result, patients who are unable to afford this formula must resort to alternative therapies, which may be less effective in treating their disease. Some insurance carriers offer coverage only if the formula is delivered via a surgically-placed feeding tube, even if the patient is able to orally consume the formula.

Patients & Providers for Medical Nutrition Equity calls on Congress to address this issue by co-sponsoring the bi-partisan Medical Nutrition Equity Act (S. 1194/ H.R. 2587). Please contact the offices of Senator Grassley, Senator Casey, Rep. Herrera Beutler or Rep. Delaney today.



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James DeLano, Hoover, Alabama

James DeLano is a 12-year-old boy who has lived his life with rare, chronic disease. As a young child, James was diagnosed with an eosinophilic gastrointestinal disease and inborn error of metabolism. Due to the many issues that his conditions caused to his digestive tract, James was prescribed medical foods (formula) at the age of 4 to ensure proper nutrition and help him to gain weight. Over the course of the next few years, James was to the point that he relied 100% on elemental formula. He eventually had a feeding tube inserted. James's formula was covered by private insurance through his father Jim's employer for a few years until the employer changed to insurance providers that did not provide coverage for the formula that James needed. The DeLano family soon found themselves in the position of having to navigate the system by themselves to facilitate a plan exception from Jim's employer to get the formula coverage.



Even after the exception was made, the family's claims for coverage continued to be denied. "I was spending at least 12 hours each week filing claims, addressing denials, researching, and providing information to the insurance company and the employer," shares James's mother, Victoria. "It was time away from a sick child who desperately needed that quality time with us, and we needed to devote that time to him. But we simply couldn't afford to pay an estimated \$1,500 a month on formula." "Due to the volume of formula needed to keep James alive, we could not buy it off the shelf from a store. We had to go through a medical supply company, and you cannot self-pay there. It was frustrating." It was then that Jim made a drastic decision - to leave the job he had for more than 20 years so that he could find an employer with health benefits that covered the special formula his son needed. "We worked to have a special plan exception made for formula coverage through Jim's new employer," Victoria said. "We were excited that coverage seemed to be falling into place, but our heart sank when our first claim was denied through the new insurance company. It was back to the drawing board, fighting the denials and providing the same documentation over and over again. Although it has settled now, we live each day with uncertainty and fear about formula coverage in the future. James depends on it for survival." "What would it mean to our family to have federal legislation that provided consistent coverage of medical foods like elemental formula prescribed for eosinophilic gastrointestinal diseases? It would mean health stability for our son. It would mean financial stability for my family. It would mean that my husband would be free to pursue whatever professional opportunities he wishes, without having to factor in whether or not the employer's insurance plan would cover the therapy prescribed to our son."

James and children like him across the country are depending on YOU to co-sponsor the Medical Nutrition Equity Act (S. 1194/H.R. 2587). Please contact the offices of Senator Grassley, Senator Casey, Representative Herrera Beutler or Representative Delaney today!



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EOSINOPHIL-ASSOCIATED GASTROINTESTINAL DISEASE

Remington Walls, Land O Lakes, Florida

Remington Walls is a 17-year-old high school senior who was diagnosed with eosinophilic esophagitis as a toddler. By the time he was 3 years of age, it became clear that food was worsening his condition. By taking so many foods out of his diet, he was at risk for malnourishment, so the doctor prescribed elemental formula. After a few months, it was determined that the best course of action for him was to remove all foods from his diet. Any food he tried to eat would make him violently sick. He gagged, vomited and was in constant pain. We had no choice but to nourish him only with the special formula. Remington continued to try to add food back into his diet over the years, all with the same result. He continues to rely on elemental formula as a sole source of nourishment. Up until last year, the Walls family was fortunate to have insurance coverage for Remington's formula through a self-funded insurance plan. When they had to change plans, family was devastated to learn that coverage was no longer offered. The Walls family had no other option at that time than to pay out-of-pocket for the formula that Remington needed to survive. Remington is now approaching adulthood, and the amount of formula he needs to live has increased over the years, resulting in an estimated \$26,000 annual expense. That's more than \$2,000 a month – the equivalent of an extra mortgage payment for some. "We are your average American family," says Remington's mother, Stephanie. "I am a teacher. My husband is a line man. We simply don't have the means to cover this therapy. And it's his only option." Until there is a cure for this terrible disease, Remington must have this formula to keep him alive. "Last year, when we faced the reality that his formula was no longer covered by insurance, we worried about how we were going to meet his needs. Fortunately, Michael's employer graciously agreed to cover Remington's therapy," says Stephanie. In the fall, Remington will be headed off to college and is already taking into consideration how formula coverage could impact his hopes, dreams, and potential. In addition to common stressors for teens his age, Remington also worries about how he will afford therapy and nourishment as a newly independent adult. "My future direction – who I will work for, where I live – will be determined by which employer offers an insurance plan that covers my treatment," Remington shares. "I feel that not having insurance coverage of medical foods will greatly impact my potential and ability to pursue opportunities in life. I already have to overcome so much more than kids my age but unfortunately am concerned with how I'll be able to financially sustain myself after college." "Medical foods aren't a diet preference," Stephanie underscores. Remington would love to be able to eat food like his friends do, to have freedom to travel without immense planning to ensure he has enough formula and a way to carry it, to worry about his education and not about how he will manage the financial strain himself as he enters adulthood. And that's not fair. That's not the American way."



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