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The FPIES Foundation PO BOX 304 Stewartville, MN 55976

www.thefpiesfoundation.org contact@thefpiesfoundation.org

Dear Representative Vickrey:

This letter is written for additional support for insurance coverage and/or reimbursement for medical food, medical necessary formula in the state of Kansas.

Children diagnosed with, or being seen by a provider for, Food Protein Induced Enterocolitis Syndrome (FPIES) may have unique nutritional needs. Infants allergic to cow's milk and/or soy who cannot tolerate standard infant formulations depend on the specific formulation of formulas designed to be hypoallergenic (elemental or, if tolerated, hydrolysates) to provide essential nutrition in infancy. After 1 year of age, children living with FPIES may have multiple allergens they are avoiding which could lead to nutritional deficiencies, without these formulas providing complete or supplemental nutrition specially designed to meet their dietary needs.

Formulas designed to be hypoallergenic are specifically formulated to meet the nutritional needs of individuals with severe and/or multiple food protein allergic conditions, including FPIES, who are unable to tolerate whole food proteins, and are often essential for normal growth and development for these children who may otherwise experience failure to grow and gain weight and/or failure to thrive.

As a prescribed management of this allergy, these formulas may be the main or only source of nutrition for an undetermined amount of time and is a critical component of the treatment of this allergy. Without these formulas, children diagnosed with multiple protein allergies may experience more complications, which can result in hospitalizations. Children unable to consume enough formula to meet the nutritional requirements for proper growth and development may be considered for alternative feeding methods such as insertion of a feeding tube (NGT/NJT, G-tube/G-J Tube or parental nutrition); however these methods may not be necessary when the child can safely and adequately consume these formula's orally without medical need for alternative feeding methods.

The cost of this formula for the families of these children is cost prohibitive when not covered by insurance. Your approval of this request for assistance with medical care and reimbursement of the formula would have a significant positive impact on this patient's health.

Sincerely,
Joy Meyer
Co-Director
The FPIES Foundation