



# HOW COVERAGE OF MEDICAL FOODS CAN SAVE LIVES & COSTS

## FOOD PROTEIN INDUCED ENTEROCOLITIS SYNDROME

FPIES is a type of food allergy that affects the gastrointestinal tract. Classic FPIES reactions typically occur two or more hours after ingesting the “trigger” food and typically involve profuse vomiting, diarrhea, and can progress to shock. Reactions can be severe and require immediate medical attention. Chronic FPIES reactions are typically characterized by increasingly severe/intermittent vomiting, chronic diarrhea and possibly progressing to an illness mimicking a severe total-body infection in addition to potentially difficulty gaining or maintaining weight. There are no simple tests to diagnosis FPIES. Additionally, there are no FDA approved therapies for the treatment of FPIES. The main treatments are avoidance of trigger foods with a personalized dietary plan that ensures proper nutrition.

Children diagnosed with or being seen by a provider for FPIES may have unique nutritional needs. These unique needs extend past the first year of life. After one year of age, children living with FPIES may have to avoid multiple foods which could lead to nutritional deficiencies. Medical foods, such as nutritionally complete formulas, provide complete or supplemental nutrition specially designed to meet their dietary needs.

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 are a critical component of the treatment of this allergy.

Many insurance companies will only provide coverage for these formulas if they are administered via a feeding tube. Many children are able and willing to drink these formulas and do not require an alternative method of administration, such as a feeding tube.

The cost of these formulas for families is cost prohibitive when not covered by insurance. The daily use of these formulas can have a significant positive impact on the quality of life for the child and the child’s family.

**The formulas may be available at certain retail stores or can be purchased directly from the manufacturer. Without insurance coverage or assistance from any advocacy programs, families may spend \$36 to \$46 per can. Depending on the age of the child and ability to eat solid food, a child may need 2.5 cans or more each week. This can cost a family a minimum of \$360 each month just to feed one family member.**

## CASE STUDY

Sarah, who lives near Atlanta, GA, was a healthy baby, born full term to a mom who had a normal and healthy pregnancy. She was breastfed exclusively until four months old. The first time Sarah’s mom introduced rice cereal, Sarah became very ill a few hours after eating. Sarah’s pediatrician diagnosed her with a gastrointestinal virus and told her to give her only breast milk for a few days. About one week later, Sarah started vomiting and had diarrhea after eating rice cereal and this time Sarah was admitted to the hospital.

She was diagnosed with FPIES and now Sarah’s family was faced with the challenge of finding foods that would not trigger an episode of vomiting and diarrhea.

Sarah is not able to eat rice, oatmeal, drink milk or eat anything that contains milk; she has to avoid all foods that contain soy and must also avoid several fruits. She is often tired, fussy, gets colds and has not been growing well or meeting her developmental milestones.

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A registered dietitian recommended the use of a hypoallergenic formula to give her the calories, protein, fat, vitamins, and minerals she needs to grow well and be healthy. Sarah is willing to drink the formula and the amount that was recommended by the dietitian. However, her family is unable to get insurance coverage for it which has placed an enormous financial burden on the family. Without the addition of the medical food to her daily routine, Sarah will continue to have nutritional deficits that will impair her growth and may impair her cognitive development.

Sarah depends on medical nutrition to keep him healthy and growing. She, and children like her 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.