



Food Protein-Induced Enterocolitis Syndrome (FPIES) Fact Sheet

Imagine something as simple as a bite of rice cereal sending your child into a fit of vomiting so violent that he/she must be rushed to the ER. This is the life of an FPIES child. Imagine a day-to-day reality of not knowing which foods are safe to feed your child and which will cause harm. If you're lucky, you have a team that includes an allergist, a gastroenterologist and a nutritionist to help your family navigate the murky waters of an FPIES diagnosis. But all too often, treatment can be delayed by misdiagnosis and misguided management of this rare and poorly understood condition: Food Protein-Induced Enterocolitis Syndrome.

What Is FPIES?

FPIES is a cell-mediated (delayed hypersensitivity) immune reaction in the gastrointestinal system. Reactions are delayed and begin as soon as 2 hours after ingesting a “trigger” food. The reactions are characterized by profuse vomiting and diarrhea. The most common triggers are milk and soy, but any foods (even those thought to be hypoallergenic) can cause an FPIES reaction.

“Although you will not see an immediate reaction as you would with a “regular” allergy (hives, swelling, anaphylaxis), the delayed reaction of FPIES can be very dangerous, painful, and long lasting.”

In about 20% of cases the child will have such an extreme reaction to a food that they will go into shock and need to be taken to the ER for immediate treatment. At this time few doctors recognize FPIES and parents must carry a letter from the child's own doctor to present to ER staff.

Due to the major lack of awareness, most parents bring their chronically reactive child into the ER or doctor's office, repeatedly being told each time that their child has reflux, a viral infection, or the stomach flu. When FPIES is finally diagnosed, infants are taken off offending foods and exclusively breast fed or given an elemental medical formula. Foods are trialed one at a time to identify safe foods vs. trigger foods.

The FPIES Diet

Many children have only one trigger food and are able to eat a normal diet otherwise. Others have a few safe foods but some don't have any. These children rely on a diet of breast milk (where moms may have to eat a special diet) or an elemental medical formula.

Although it is likely that there are safe foods for all FPIES children, the process of finding them is extremely painstaking. Each food must be trialed slowly while parents look for reactions before they are “full blown.” When a reaction does occur, healing can take days to weeks before a new food can be trialed.

The FPIES Family

The FPIES family is overwhelmed with daily challenges of managing their child’s condition. The many trials parents and caregivers face include:

- Slowly, methodically trialing foods and trying to recognize the symptoms of a reaction.
- Helping their child through the pain, discomfort, and lingering effects of a reaction.
- Keeping their child safe from all foods that are unsafe or unknown.
- Helping their child cope with being denied the basic human desire to eat food.
- Researching their child’s condition.

“An FPIES child often looks healthy on the outside. It is what is going on inside and the cost of staying healthy that is debilitating for the FPIES child and family.”

All these things are added to the normal stressors of family life/work, school, kids, etc.

Why Research?

- Little is known about FPIES.
- Few doctors are able to recognize and diagnose the syndrome.
- There is currently no cure or treatment for FPIES.
- While seminal studies report that children may outgrow FPIES between ages 2 and 3, many families are finding that this is not the case for their child.
- There are a variety of symptoms among FPIES children that are currently not recognized by the medical community as being related to FPIES.
- More research is needed.

You Can Make a Difference

The International FPIES Association (I-FPIES) was created in 2011 to develop in-depth research, provide widespread education to medical professionals, and establish supportive services for children and families affected by FPIES. I-FPIES actively funds new research at leading medical centers specializing in FPIES, and the answers are beginning to emerge.

Please consider a monetary donation to I-FPIES. Remember, when you diagnose an FPIES child, you diagnose an entire family. For more information and to make a donation, please visit www.fpies.org.

About the I-FPIES

The International FPIES Association (I-FPIES) is a non-profit organization whose mission is to

improve the quality of life for patients and families affected by Food Protein-Induced Enterocolitis Syndrome (FPIES) by means of education, research, advocacy and support. I-FPIES is a worldwide leader in FPIES awareness and the issues surrounding this condition. We seek to increase awareness by providing educational resources, support services, advocacy, and the development of groundbreaking research through our partnership with the medical community.