

# Food Protein-Induced Enterocolitis Syndrome (FPIES):

A rare type of <u>non IgE mediated</u> food allergy affecting the gastrointestinal (GI) tract.

Keep in mind, children living with FPIES may not follow typical feeding patterns or milestones and will benefit greatly from individualized goals.

#### Be Aware:

- \*Food allergens can be present in nonfood products such as play dough, crayons, bubble bath, lotions, soaps, sunscreen, paper/ink, etc. A child *may* experience symptoms from ingestion or exposures to these non-typical items
- \*Medications, Supplements, Vitamins may have food allergens in ingredients
- \*Although there is currently no medical explanation, some children seem to do better on one elemental formula over another.
- \*If corn allergy is a concern, a corn-free formula or modular formula may be needed.

### Nutrition management key considerations:

- \*Food journaling, noting potential non-food or trace protein exposures, can help identify triggers
- \*A nursing mother may need an elimination diet plan if child is reacting through breast milk.
- \* Typically elemental formula is recommended but extensively hydrolyzed may be tolerated
- \* Be aware of potential micronutrient deficiency risks when eliminating multiple foods
- \*Parents may need assistance when transitioning to bottle from breast, if formula transition becomes necessary for a breast-fed child.
- \*Assurance of maintaining adequate nutrition when weaning (from formula or breastfeeding), being aware formula/breastfeeding may be extended.
- \*Oral aversion may develop and require intervention from a knowledgeable feeding team
- \*Maintenance of normal gains in height as well as weight, or catch-up growth. Z-scores from the WHO charts may be helpful in clinically tracking the gains in FTT children. This often requires very creative supplementation when a number of foods or food families must be avoided.
- \*Provide resources that may offer helpful recipes, such as grain-free, gluten-free/celiac, dairy/soy-free, avoiding corn, etc.
- \*Children with many triggers, many failed trials, or inadequate nutrition may exhibit developmental delay.

For food journal samples and templates, please visit: <a href="http://fpiesfoundation.org/toolboxfood-journal/">http://fpiesfoundation.org/toolboxfood-journal/</a>
For cooking & recipe tools for families please visit: <a href="http://fpiesfoundation.org/cooking-and-recipes/">http://fpiesfoundation.org/cooking-and-recipes/</a>



### A Multidisciplinary Team Approach:

A knowledgeable and compassionate medical team can help this diagnosis to become manageable and enable those affected by it to thrive with the help of proper management strategies.

**Pediatrician/ Family MD:** Track growth and development, screen for developmental delays, feeding/oral aversions, addressing psycho-social needs.

The Allergist: Provides testing for IgE allergies, establishment of protocol for trials at home or scheduling of in-office/hospital trials, treatment plan in case of reaction, immune modulating medications if needed, ER letter. And will collaborate with RD for food trials based on nutritional needs.

The Gastroenterologist: Performs endoscopy, ruling out other similar GI disorders, tube feeding placement and instructions if needed, reflux control, coordinate with RD on nutritional management and goals.

**The Dietitian**: Provide guidance and education on the safe introduction of foods with goal of achieving a somewhat "normal" diet for age with appropriate variety, textures despite restrictions due to FPIES.

**Supporting Staff:** May include ST/OT feeding teams, genetics, Early Intervention/social workers, case management, WIC, IBCLC, counseling/play therapy.

### Nutrition care plan goals:

- \*Maintain age appropriate gains in weight, as well as linear height, with considerations for any need for catch-up growth (considering parents' and siblings' growth curves in establishing goals).
- \*Establish food trial protocol/ procedure prescribed by Allergist utilizing a team approach on a schedule that allows for normal weight gain and developmental gains, particularly if there are many triggers.
- \*Food journaling instructions may require counseling on food ingredient labels, food additives, non-labeled things such as produce washes, anti-caking additives, etc.
- \*Addressing and avoiding oral aversion, in conjunction with feeding team if needed.
- \*Instructions for elimination diet possibilities if mom is nursing, to maintain her nutritional status.
- \* Availability and assistance of resources such as WIC, insurance coverage support for formula.

For additional information, tools and resources for families please visit:

<a href="http://fpiesfoundation.org/cooking-and-recipes/nutrition-resources-for-families/">http://fpiesfoundation.org/cooking-and-recipes/nutrition-resources-for-families/</a>

For Advocacy and Documentation tools, please visit:

<a href="http://fpiesfoundation.org/advocacy/">http://fpiesfoundation.org/advocacy/</a>

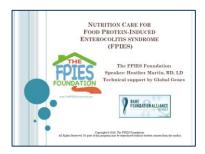


While yearly check-ins with their Dietitian will be sufficient for many children diagnosed with FPIES, others may require more frequent support and monitoring.

#### This may be due to:

- Limited list of safe foods
- Incomplete nutrition due to multiple restrictions
- Feeding aversions due to past experiences
- Poor growth
- Help with transition from baby foods to table foods
- Tube feeding protocols

Looking to learn more? Don't miss our FREE Nutrition Webinar!



To register, go to www.fpiesfoundation.org

## **Key Considerations in Long Term Management:**

- \* Elimination diet to avoid known allergen triggers and promote healing
- \*Extended use (past 1 year) of formula may be necessary
- \*Consider consultation with OT/ST for best formula administration measures
- \*Evaluate type/amount of formula needed to maintain growth,
- \*Assess need for catch up growth and figure nutrient needs accordingly
- \*Tube feeding protocols if needed
- \*Confounding issues such as oral aversion.
- \*Co-occurrence of sensory disorders, Eosinophilic Esophagitis, development of IgE allergy, etc; and education regarding difference in treating the types of reactions
- \*Social development/family relationships may suffer if parents fear social settings where avoidance of triggers is complicated or impossible. Parents may need support in developing new traditions for holidays and birthdays, and in dealing with unsupportive family members or caregivers.
- \*School age children may require an IEP/504 plan.

For additional information, tools and resources for nutrition professionals please visit: <a href="mailto:fpiesfoundation.org/professional-resources-nutrition/">fpiesfoundation.org/professional-resources-nutrition/</a>
For School resources, visit our For Kids corner: <a href="http://fpiesfoundation.org/a-foundation-for-kids/">http://fpiesfoundation.org/a-foundation-for-kids/</a>
Still have more questions? Contact us today at: <a href="mailto:contact@thefpiesfoundation.org">contact@thefpiesfoundation.org</a>



#### **References & Articles of interest:**

- 1. Rhonda Mattingly. "Optimizing an Aversion Feeding Therapy Protocol for a Child with Food Protein-Induced Enterocolitis Syndrome (FPIES)" J Pulm Respir Med 2015, 5: 287
- 2. Miceli Sopo, S., I. Dello Iacono, et al. (2014). "Clinical management of food protein-induced enterocolitis syndrome." Current Opinion in Allergy and Clinical Immunology 14(3): 240-245.
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- 5. Meyer, R., N. Rommel, et al. (2014). "Feeding difficulties in children with food protein-induced gastrointestinal allergies." Journal of Gastroenterology and Hepatology 29(10): 1764-1769.
- 6. Kabuki, T. and K. Joh (2007). "Extensively Hydrolyzed Formula (MA-mi) Induced Exacerbation of Food Protein-Induced Enterocolitis Syndrome (FPIES) in a Male Infant." Allergology International 56(4): 473-476.

#### **Authors and Contributors:**

Jen Hertsch MS,MBA Amanda LeFew MT-BC Bailey Koch, RD, CSP, LD Heather Martin, RD, LD Joy Meyer, DTR

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