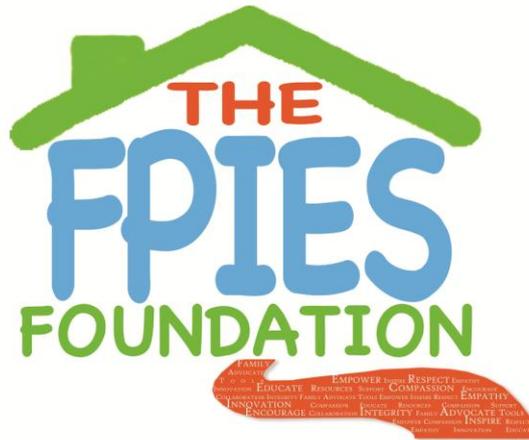


NUTRITION CARE FOR FOOD PROTEIN-INDUCED ENTEROCOLITIS SYNDROME (FPIES)



WWW.THEFPIESFOUNDATION.ORG

The FPIES Foundation
Speaker: Heather Martin, RD, LD
Technical support by Global Genes



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PRESENTERS

Heather Martin, RD LD

FPIES Foundation volunteer

Heather has been a registered and licensed dietitian in clinical practice since 2011. She is a former certified childbirth educator and has a long-term special interest in maternal and child health, as well as general wellness nutrition, disordered eating, and nutrition support. As the mother of a 5-year-old child with FPIES and IgE allergies to multiple foods, she has gotten her most valuable experience in the nutritional management of these conditions the hard way.



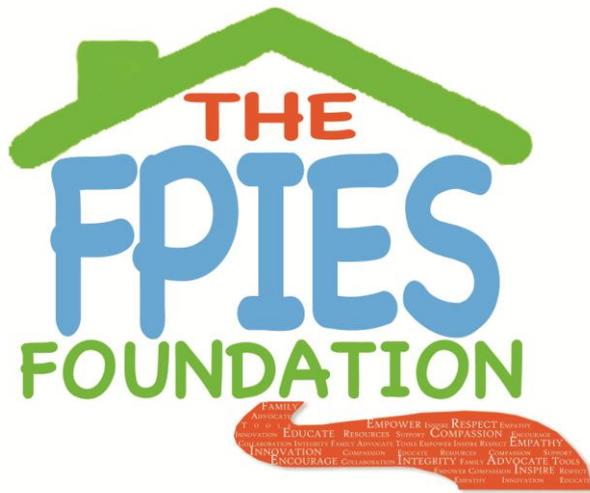
Joy Meyer, DTR

FPIES Foundation Co-Director

Joy has an Associates degree in Nutrition and is a Registered Dietetic Technician (DTR). Joy is the mother of four sons, the youngest who is 7yrs.old and continues to live with FPIES on a limited diet. Joy has a love for Nutrition and a passion for helping others. Joy is a Foundation Founding Member and Executive Co-Director.



MISSION



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The FPIES Foundation is dedicated to overcoming the challenges of Food Protein-Induced Enterocolitis Syndrome by offering tools for education, support, and advocacy to empower families and the medical community.



Objectives

The purpose of this webinar is to aid nutrition professionals by providing nutritional care plan guidelines, expert tips and tools, as well as numerous resources to assist them as they monitor and provide care for their patients living with FPIES.

Goals for Nutrition Care for FPIES Webinar:

- ✓ Understand what FPIES is; how is it diagnosed and treated
- ✓ Know how to identify acute and chronic reactions & symptoms
- ✓ Gain a better understanding of food trials and/or elimination diet and how to monitor and assure adequate nutrition for optimal growth and development
- ✓ Learn nutrition considerations identified for long-term care management

Please find a PDF of this webinar, along with Nutrition worksheets and additional FPIES resource links, at www.fpiesfoundation.org

ABOUT FPIES

Food Protein-Induced Enterocolitis Syndrome (FPIES) is a Non-IgE Mediated allergy affecting the gastrointestinal (GI) tract.



"...With the help of other FPIES families, we are coping, handling and even growing stronger as a family because of it" – An FPIES mom



FPIES (Food Protein-Induced Enterocolitis Syndrome) is a rare type of food allergy affecting the gastrointestinal tract. Classic FPIES reactions occur 2 or more hours after ingesting the "trigger" food and typically involve profuse vomiting, diarrhea, and can progress to shock.

There is no cure for FPIES and there are no diagnostic tests to confirm diagnosis. Food trials are the only way to determine whether or not a food is safe for each child. Any food can trigger an FPIES reaction and different children react to different food(s).

FPIES is not well-known, even within the medical community, and awareness is desperately needed to facilitate better diagnosis and symptom management for affected children. Together, we can raise awareness and help to improve the quality of life for affected children and their families.

The FPIES Foundation is an Incorporated 501(c)3 Non-profit Foundation whose mission is dedicated to overcoming the challenges of Food Protein- Induced Enterocolitis Syndrome by offering tools for education, support, and advocacy to empower families and the medical community.

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What is FPIES?

FPIES (Food Protein-Induced Enterocolitis Syndrome) is a type of food allergy affecting the gastrointestinal (GI) tract.

Symptoms:

- The classic pattern of an FPIES reaction following the ingestion of a trigger food is the delayed onset (2-3 hours or more) of dramatic symptoms, including severe and repetitive vomiting and diarrhea possibly leading to sepsis-like shock.
- The chronic reaction pattern includes increasingly severe vomiting, diarrhea, and poor growth, possibly progressing to an illness mimicking a severe total-body infection.

Triggers:

- In the first months of life, FPIES reactions are most often caused by cow's milk protein formula, and sometimes by soy; proteins in breast milk may also cause symptoms in some infants.
- For infants experiencing FPIES with solid foods, rice and oats are the most common triggers. Any food protein can trigger a reaction, some children may react to 1-2 foods whereas others may experience reactions to multiple foods.

Testing:

FPIES is a non-IgE food allergy. Unlike typical food allergies, symptoms may not be immediate and do not include hives, swelling or wheezing, and do not show up on standard allergy tests.

An FPIES diagnosis is usually made by an allergist or gastroenterologist and takes into account patient history, as well as ruling out various other possible conditions.

Treatment:

- FPIES reactions are severe. Immediate medical attention is needed for IV hydration and monitoring.
- With proper medical attention and a personalized dietary plan to ensure proper nutrition, children with FPIES can grow and thrive.



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<http://fpiesfoundation.org/about-fpies-3/>

SYMPTOMS

There are two ways that infants or children with FPIES might come to medical attention:

Acute

- Repetitive, profound vomiting (most commonly average ~2-3hrs post ingestion)
- Diarrhea (~2-10hrs post ingestion)
- Dehydration
- Lethargy
- Pallor (pale skin, blue/grey tones)
- Hypotension/Hypothermia
- Abdominal Distention

Chronic

- Intermittent/Chronic vomiting
- Chronic watery diarrhea with blood/mucus
- Weight loss
- Failure to Thrive
- Lethargy
- Pallor
- Abdominal Distention

Is it FPIES? <http://fpiesfoundation.org/is-this-fpies/>

RED FLAGS THAT YOUR CLIENT MAY BE EXPERIENCING FPIES SYMPTOMS



- Episodes of severe vomiting, often occurring “out of the blue” a few hours after eating
- Frequent diarrhea and/or blood in stools
- Episodes of lethargy/shock- hours after feeding that have resulted in ER visits
- May see as failure to thrive

Keep in mind that although these symptoms may be seen with an FPIES diagnosis, there is a very wide range of symptoms and severity of symptoms



THE PARENT MAY REPORT

- *“When I gave baby cereal for the first time, my child seemed to experience symptoms of a stomach bug”*
- *“My infant takes several months to outgrow his/her clothes”*
- *“My child spits up in very large amounts— I worry that he/she isn't keeping much of the milk/formula down”*
- *“My child has more frequent 'blowouts' than I have ever seen”*
- *“My child seems very disinterested in/ seems fearful of food”*



Other symptoms commonly noted for intolerances may also be reported



A CLINICAL DIAGNOSIS

- Diagnosis made by Allergist or Gastroenterologist
- Easily misdiagnosed: Not your typical food allergy!
 - Symptoms not immediate & do not show up on standard allergy tests or biopsies, unless IgE also present as in Atypical FPIES.
 - Negative allergy evaluation may delay the diagnosis and take the focus off the causative food.
 - Blood tests during acute reaction mimic the body's response to infection.
 - Atopy Patch Testing not validated but may be helpful
 - Symptoms can mimic other disorders
 - May present acutely or chronic and mimic other disorders of infancy, additional symptoms secondary to reactions may be present (making it more difficult to pinpoint diagnosis)
- Oral Food Challenge
 - The most definitive test, however not often needed initially if the doctor has excluded other diagnosis and the medical history is consistent with FPIES.



COMMON TRIGGER FOODS

- Milk/Soy most common trigger
- Rice/Oats most common solid food trigger
- **Any** food protein can be a trigger
 - Proteins in breast milk may also cause symptoms in some infants
- Some children may react to one or two foods whereas others may experience reactions to multiple foods
- Other common triggers that include, *but are not limited to* barley, poultry, peas, green beans, sweet potatoes, and squash
 - Common triggers foods common triggers may differ by region



FPIES REACTIONS CAN BE SEVERE AND MAY REQUIRE EMERGENCY MEDICAL ATTENTION

SHOCK & DEHYDRATION IN ACUTE FPIES REACTIONS

FPIES (Food Protein-Induced Enterocolitis Syndrome) is a rare type of non IgE food allergy. Acute FPIES reactions cause severe vomiting and/or diarrhea 2+ hours after ingesting a trigger food. This can cause dehydration and may progress to shock, a life-threatening reaction.

Dehydration

A medical condition that occurs when the body loses more fluids than it is taking in, when blood pressure drops and body systems begin to shut down. There is not enough blood flow and oxygen delivery.

- Sunken eyes
- Dry cracked lips
- Decreased skin elasticity
- Decreased urination

Seek medical intervention immediately to avoid shock; progression can be stopped with appropriate treatment.

Laboratory results that support dehydration are blood work and urine.

Compensated Shock

A medical condition that occurs due to the body's attempt to compensate for excessive fluid loss.

- Extreme thirst
- Restlessness and progressive anxiety
- Weakness
- Tachycardia (fast heart rate)
- Decreasing pulse strength
- Prolonged capillary refill
- Pallor
- Cool and moist skin
- Eventual "air hunger"
- Decreasing blood pressure
- Mottling of skin

There is a need for emergency medical treatment in order to prevent further progression.

Decompensated Shock

This occurs when the body's compensation strategies begin to fail, and signs and symptoms of shock become more apparent.

- Pulse difficult to detect (too fast or too slow)
- Altered state of consciousness
- Disorientation/confusion
- Grey/ashen skin
- Cold and dry skin
- Rapid drops in blood pressure

THIS IS A LIFE-THREATENING MEDICAL EMERGENCY.

With progression of shock, end-organs do not get blood flow and are deprived of oxygen. Blood does not flow to remove waste products. The body becomes more acidic. A blood sample from an artery may be needed to assess this.

Shock is a serious medical condition and can progress rapidly in young children. The FPIES Foundation does not provide individualized medical advice, diagnosis, or treatment. The information provided is intended for supportive, awareness and educational purposes and not as medical advice. It is not a substitute for care by a trained medical provider.

Shock can only be assessed by a medical professional.

If your/the child is experiencing symptoms noted above call your health care provider immediately or call for 911 for help.



For more information: www.fpiesfoundation.org

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TREATMENTS

Treatment for Acute Reactions:

- IV Fluids main therapy
 - Steroids (IV or oral)
 - Zofran (IV or oral)
- Supportive care
- Temporary bowel rest/TPN in severe cases
- Labs/stool test during acute reactions

Treatment for Chronic Reactions:

- Dehydration treatment
 - Oral rehydration protocol
 - IV hydration protocol
- Acute following chronic reaction risk
- Action Plan
- Long term considerations in care

Nutritional Care Plan considerations following reactions

- Child may limit intakes
- Monitor growth for malabsorption
- Monitor labs



PROGNOSIS

FPIES usually resolves with time, patients will need to be closely followed by their medical team to discuss what foods are safe to eat and when it may be time to determine if FPIES has resolved.



With proper medical attention and a personalized dietary plan to ensure proper nutrition, children with FPIES can grow and thrive.



DIETITIAN'S ROLE

- Acknowledge support
- Ensure adequate growth and development
- Suggestions of foods to try to balance diet
- Micronutrient requirements on restricted diets
- Recipe modification with limited ingredients
- Tube feeding protocols if needed
- Monitoring of growth
- Communication with the medical team
- Give hope!



GOALS TO ADDRESS WITH A FAMILY UNDERGOING AN FPIES EVALUATION (OR NEWLY DIAGNOSED)

- Food Journaling
- Label reading
- Alternative recipes resources
- Meal planning strategies
- Nutritional diversity



- Breastfeeding support
- Medical Food, when necessary
- Food introduction (with Allergist)
- Encourage families, caregivers, and patients to ask for support when needed



BE AWARE, CONSIDERATIONS IN CARE

Triggers can be found in non-food items

- Craft supplies
- Soap/lotion/bubble bath
- Paper/Ink

Allergens may be found in the ingredients of:

- Medications (can be compounded)
- Supplements (such as probiotics)
- Vitamins (allergen friendly varieties available)



Typically elemental formula is recommended

- Extensively hydrolyzed may be tolerated
- 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 education for family
- A nursing mother may need an elimination diet plan
- Micronutrient deficiency when eliminating multiple foods
- Maintaining adequate nutrition when weaning to/from formula
- 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
- Provide resources that may offer helpful recipes, such as grain-free, gluten-free, dairy/soy-free, avoiding corn, etc...
- Children with many triggers, many failed trials, or inadequate nutrition may exhibit developmental delay



KEY CONSIDERATIONS IN LONG TERM MANAGEMENT

- Elimination diet
- Extended formula
- OT/ST consults
- Catch up growth
- Tube feeding protocols if needed
- Co-occurrence of other disorders
- Psycho-Social development
- School age children may require an IEP/504 plan



FOOD INTRODUCTION GUIDE



Helpful hints:

- ❖ Recommendations should include introducing cooked foods vs. raw/uncooked first
 - ❖ Studies show that children with IgE and FPIES tend to have a longer/more complex course.
 - ❖ Studies show that children with cross-over of dairy/soy and rice/oats acute triggers tend to have other/multiple triggers.
 - ❖ Children living with FPIES may not follow typical feeding patterns or milestones and will benefit greatly from individualized goals.
- Hypoallergenic foods on IgE allergy lists do not apply to FPIES
 - Lists designed for EGID's are not designed for FPIES
 - Be sure Elimination Diet list recommendation is FPIES friendly
 - Food family lists may be beneficial to expand idea's for trials
 - Shared parent success reports can be encouraging and empowering, such as: <http://fpies.bofferding.net/fpies-food-survey.html>

Please note: studies are not yet available on food introduction in FPIES, these are recommendations based on current literature and clinical experiences



NUTRITION CARE PLAN GOALS

- Maintain age appropriate gains in weight, as well as linear height
- Establish food trial protocol/ procedure prescribed by Allergist
- Food journaling instructions may require counseling
- Addressing and avoiding oral aversion
- Instructions for elimination diet
- Assistance and availability of resources

With a proper nutritional plan, children can grow and thrive!



MONITORING

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



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.



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- Medical Advisory Board of The FPIES Foundation



ADDITIONAL HELPFUL LINKS

- For Healthcare professionals:
<http://fpiesfoundation.org/for-healthcare/>
- For Nutrition Professionals:
<http://fpiesfoundation.org/professional-resources-nutrition/>
- Nutrition resources for families:
<http://fpiesfoundation.org/cooking-and-recipes/nutrition-resources-for-families/>
- Cooking & Recipes: <http://fpiesfoundation.org/cooking-and-recipes/>
- Food Journals: <http://fpiesfoundation.org/toolboxfood-journal/>
- Register to follow research on the Global Registry!
<https://connect.patientcrossroads.org/?org=fpies>



THANK YOU!

