

# About FPIES & A Parent Perspective

Presented by:  
Joy Meyer, DTR  
Co-Director of The FPIES Foundation

## Learning objectives:

- Understand what FPIES is; how is it diagnosed and managed
- Recognize the parent perspective of having a child diagnosed with FPIES
- Learn ways you can help a family living with FPIES



Food Protein-Induced Enterocolitis Syndrome

# About the Presenter



Joy Meyer, DTR has an Associates degree in Nutrition and is a Registered Dietetic Technician (DTR). Joy is a busy wife and mother of four sons, the youngest who is 8yrs.old 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 of The FPIES Foundation.

# A Foundation for FPIES



[WWW.THEFPIESFOUNDATION.ORG](http://WWW.THEFPIESFOUNDATION.ORG)

The FPIES Foundation is a 501(c)3 non-profit 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.

# What is FPIES?

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

## Have you heard?

*There are different  
types of food allergies...*

**Food Protein-Induced Enterocolitis Syndrome ("F-PIES") is a rare but serious type of food allergy.**

- Symptoms of a reaction are delayed and may occur hours after exposure.
- Although there are '**common trigger**' foods, any food can cause an FPIES reaction.
- A severe FPIES reaction can include profuse vomiting, pale skin, extreme sleepiness (lethargy), diarrhea, dehydration, and can quickly lead to shock.
- Signs of shock for an individual with FPIES are severe and include lethargy, pale/grey skin tones, and drastic changes in body temperature and heart rate.

*Call 9-1-1 or seek prompt medical attention in the event of a severe reaction that includes fluids or IV resuscitation. (Note: EpiPens will not stop an FPIES reaction.)*

[www.theFPIESfoundation.org](http://www.theFPIESfoundation.org)

# Symptoms

There are two ways that an infant or a child 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

It is important to note there can be a combination/overlap of acute and chronic in the same child.



## Chronic

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



# Red Flags That A Patient 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
- 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.

\*\*Symptoms may overlap with several other conditions.

# 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.



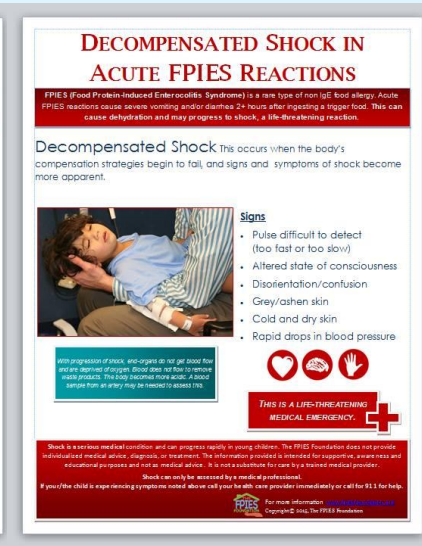
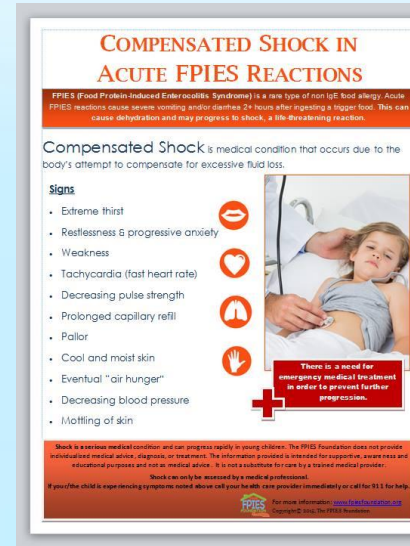
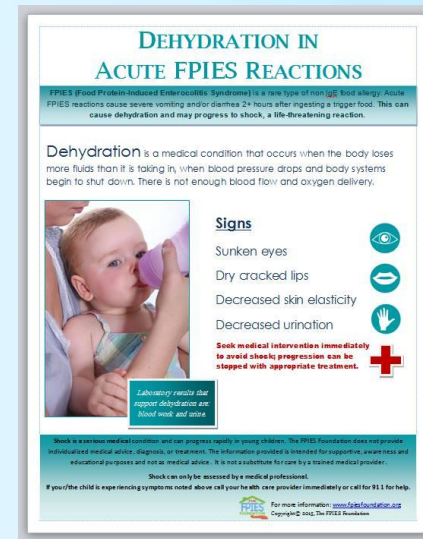


# Common Trigger Foods

- 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
- 
- A close-up photograph of a baby's face as they are being fed with a light blue spoon. The baby has a focused expression and is looking slightly upwards. Their mouth is open, and the spoon is positioned inside. The baby is wearing a white garment with a yellow trim. The background is dark and out of focus.
- Other common triggers that include, *but are not limited to* barley, poultry, peas, green beans, sweet potatoes, and squash
    - *Common trigger foods common triggers may differ by region*

# Reactions

- Are delayed post-ingestion of the trigger food
  - Acute reactions most commonly average ~2-3hrs post ingestion, however this may be shorter or longer in some cases.
  - Delayed, intermittent vomiting is seen in chronic reactions.
- Can be severe
  - It is important to get to prompt medical attention (ER/911) to avoid sepsis-like shock.
- ER Plan/ER Letter
- Action plan



Find resources at: <http://fpiesfoundation.org/emergency-care/>

# 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](http://www.fpiesfoundation.org)

Copyright © 2015, The FPIES Foundation



# Treatments

## Treatment for Acute Reactions:

- IV Fluids main therapy
  - Steroids (IV or oral)
  - Zofran (IV, IM (if no IV access), or orally)
- Supportive care
- Labs/stool test during acute reactions

## Treatment for Chronic Reactions:

- Dehydration treatment
  - Oral rehydration protocol
  - IV hydration protocol
- Temporary bowel rest/TPN in severe cases
- Acute following chronic reaction risk
- Action Plan
- Long term considerations in care



# 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.





# Dietitian's Role

## Nutritional Care Plan considerations following reactions:

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



Please visit our webpage for Nutrition Professionals:  
<http://fpiesfoundation.org/for-healthcare/professional-resources-nutrition/>

# A Life Altering Diagnosis

- The Diagnosis
  - Easily misunderstood
  - No medical tests
  - Few specialists
- Advocate and Educate
  - Family/Friends
  - Community
  - Daycare/school
  - Doctors
- Not your Typical Food Allergy
  - Delayed food allergy
  - Uncommon allergens
  - Less treatment plans
  - Rare/“Invisible Illness”

“The stress, when it first started, of having no idea what was wrong with my baby-but knowing something was wrong; including the doctors who assured me it was extended colic.”

- Kristi W



# FPIES In The Everyday

- Accidental exposure risk
- ED aware
- Food trial anxiety
- Shopping & label reading
- Creative food prep
- No simple meals
- Always plan ahead



# Living on an Island

- As a parent of children affected by FPIES, advocacy quickly becomes a 24hr-a-day job!

- We parents are always seeking new ways for our voices to be heard in hopes of bettering day-to-day life for our kids.



*"FPIES isn't a diagnosis for us, it's an island".*

Alliyson, parent of a child with FPIES



# Sharing Our Voices: A Patient Registry

The **FPIES Global Patient Registry** engages our community in surveys:

- General Health Information
- Family History
- Diagnosis-Specific Information
- Quality of Life Impact

**Affected families often express:**

- Feelings of isolation,
- Being misunderstood
- Experiencing inadequate care

**Altavoice's free patient registry platform** gave us the opportunity to create a home-base for our community's voices-- a place to be seen and heard by practitioners and researchers, worldwide.

[www.fpiesregistry.com](http://www.fpiesregistry.com)





# FPIES: A Chronic Condition?

Though acute FPIES reactions may be brief in nature, management of FPIES is an ongoing, daily process that is best addressed with multifaceted approaches, as is often the case with chronic conditions.



Nutrition Dynamics



Social/Family  
Dynamics



Physical  
Environments

# **A Multifaceted Approach for a Chronic Condition**



- At Home**
- In the Community**
- At School/Age-Appropriate Social Settings**

# Ongoing Care



Because **FPIES impacts multiple aspects of daily life**, viewing it as a chronic condition (until the time it is outgrown) can help clinic communities to better explore the nature of support needed by families between and during reactions.

# How to Help

- Help prevent accidental exposures
- Treating reactions
- Empower
- Validate
- Referrals
- Individualize care





# Offer Words of Encouragement



- Acknowledge
- Be optimistic but realistic
- Choose your words carefully

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



# The Positive Impact



- Healthy eating
- Celebrating food passes
- New recipes
- Family meals
- Food free events
- Inclusion
- Validation

# Resources

- FPIES Registry
- FPIES Provider Database
- Patient & Provider packets
- Support groups
- Website: [fpiesfoundation.org](http://fpiesfoundation.org)

5 MYTHS  
ABOUT  
FPIES



## FPIES Toolbox:

- Awareness
- Food Journals
- Healthcare professionals
- Medical Literature
- Cooking & Nutrition
- Emergency care
- For Kids/School
- Webinars & online learning
- Bilingual resources

# Questions or Comments?

