FOOD PROTEIN ENTEROCOLITIS SYNDROME (FPIES)

WHAT IS IT?
- This is a type of food allergy that affects the gut.
- It may develop in infants fed milk or soy formulas, or when certain solid foods, especially rice or oat, are introduced to breast fed babies.

WHAT ARE THE SYMPTOMS?
- While ingesting the problem food:
  - There is frequent vomiting, and diarrhea that could be bloody
  - There may be poor growth
  - The infant may become very ill appearing (weak, pale, blue)
- When the problem food has been eliminated from the diet:
  - A baby may be perfectly well while off the food but about 2 hours after eating the food the above symptoms appear and may be severe

HOW IS IT DIAGNOSED?
- Usually by a medical history and examination
- There are no simple tests to know the problem food
  - Simple allergy tests are often negative, even to problematic food
  - Your doctor may prescribe avoidance of suspect foods as a trial for diagnosis and treatment
- Sometimes a feeding test under doctor supervision is needed to identify the problem foods or, later, to see if the allergy is gone

HOW IS IT TREATED?
- The main treatment is to avoid the problem food(s)
- If there is a mistake and a food is eaten, you should go to an emergency room for treatment (which may include giving fluids into the vein, using steroids to calm the immune system, and possibly an anti-vomiting medication, ondansetron)

WILL IT GO AWAY?
- Yes, usually by 1-3 years after the reaction

WHAT SHOULD I ASK/TELL MY DOCTOR?
- Let your doctor know of any new symptoms or worsening or continuation of symptoms
- Discuss making sure your child is getting a nutritious diet
- Discuss how and when to introduce additional foods
- Discuss a plan in case the food is accidentally eaten

RESOURCES (SEE REVERSE SIDE FOR A NOTIFICATION FORM)
- This program has additional information sheets that you may find helpful
- Explore additional educational materials, for example, from Food Allergy Research & Education (www.foodallergy.org) and www.iaffpe.org and www.thefpiesfoundation.org
EXAMPLE OF LETTER FOR FAMILY OF CHILD WITH FPIES

- HAVE YOUR DOCTOR REVIEW AND COMPLETE
- THIS MAY BE CARRIED TO BRING TO AN EMERGENCY ROOM IN THE EVENT OF A REACTION/ACCIDENTAL INGESTION

Date:

RE:

DOB:

Dear Doctor (To Whom It May Concern),

The patient named above has a food allergy called **food-protein induced enterocolitis syndrome**. This is a type of allergy that usually does not result in typical "allergic" symptoms such as hives or wheezing, but rather with isolated gastrointestinal symptoms.

The foods that this child is avoiding include: ______________________________.

The symptoms of this type of allergic reaction include repetitive vomiting that may not start for a few hours (e.g., 2 ) following ingestion of the food to which the child is allergic. Even trace amounts can trigger a reaction. There is often diarrhea that starts later (after 6 hours). In some cases (~20%), the reaction includes lethargy, hypotension, acidemia, and/or methemoglobinemia. The treatment is symptomatic and can include intravenous fluids (e.g., normal saline bolus, hydration) and steroids (e.g., Solumedrol 1-2 mg/kg) for significant symptoms. The latter is given because the pathophysiology is that of a T cell response. Ondansetron, given intravenously may be effective based on one small case series.

This information is being given so that this could be considered in the differential diagnosis for this patient in the event of symptoms. Of course, this illness **does not** preclude the possibility of other illnesses (e.g., infection, toxin ingestion, etc.) or even other types of allergic reactions leading to symptoms, so it is up to the evaluating physician to consider all possibilities. Similarly, the treating physician is encouraged to pursue any other treatments deemed necessary (e.g., symptomatic such as epinephrine for shock, antibiotics for presumed infection, etc).

Please feel free to contact us for any further assistance.

Sincerely,

[YOUR DOCTOR]