

A Q&A Sampler: Questions from the FPIES Community, Answers from Our Medical Advisory Board (excerpts)

For expanded answers and additional topics, be sure to visit:

www.fpiesfoundation.org/fpies-questions-and-answers-from-the-medical-advisory-board/

My child was just diagnosed with FPIES— now what?

- 1) Get ready to go to school! The more you learn about your child's diagnosis, the better prepared you will be to serve as an advocate for his/her needs.
- 2) Prepare to partner with your physicians! Remember that you have a common goal – the health and happiness of your child. Find physicians you trust and with whom you can have open communication to help guide the way.
- 3) Get Support! Take advantage of the experience of parents who have walked in your shoes, and join a local or online support group for parents of children with FPIES. This support will be invaluable.
- 4) Get your family on board! Once you have a confirmed diagnosis, plan to sit down with key family members to help them learn about FPIES and how they can help your child stay safe and thrive.

I suspect FPIES, but what do I do if my child's doctor is not familiar with FPIES?

Because FPIES is an uncommon diagnosis, it is possible that your child's doctor may not be familiar with it. That's okay, and it is not an indication that you need a new physician. Let your doctor know what you're thinking in advance. Your physician deserves some time to educate herself about FPIES before offering an opinion. Consider a phone call, letter or email to your doctor to lay the foundation for the discussion, and include a copy of a recent medical journal review article on the topic. (Here's a suggestion: "The Current Understanding of the Immune Mechanisms of FPIES"). Ask if you can schedule an appointment to discuss the possibility of FPIES once your doctor has had an opportunity to review your child's chart and the literature.

What do I need to know about other conditions that may mimic FPIES?

In a young child, viral gastroenteritis with dehydration, sepsis (a severe infection) and anaphylaxis are conditions that may mimic FPIES during an acute symptomatic episode; abdominal surgical emergencies, such as intussusception or necrotizing enterocolitis (in infants), may also present similarly. These other diagnostic possibilities are important considerations and may lead to other diagnostic tests.

My child has additional symptoms not mentioned in the FPIES definition. Could he/she still have FPIES?

There can be variability in symptoms and they may not always match the "classical" descriptions. In severe FPIES reactions, shivering, fever or low body temperature were reported infrequently. Some children develop diarrhea with mucous or blood within 6 hours following an FPIES reaction. However, symptoms that start immediately (within minutes) following an ingestion of the food, such as itching, hives, sneezing or coughing suggest an IgE-mediated food allergic reaction, not FPIES. Remember that a child may have FPIES to one food and an IgE-mediated food allergy to other foods, or may develop sudden, IgE type reactions (hives, swelling, etc) to the FPIES trigger food. If you suspect that your child is reacting to a food, you should consult his/her pediatrician for advice and consider an evaluation by an allergist.

Why was my child able to eat his/her trigger foods one or more times before causing a reaction?

Often, allergic reactions, including FPIES do not occur on the first exposure to the offending food. Sometimes the immune system does not "attack" until there are repeated exposures. Nonetheless, there is frequently a reaction on the first "known" exposure, presumably because of some prior small exposures.

In what ways can I help my child during a reaction?

It is important to keep your child comfortable and get to medical attention for treatment. If your child has had prior severe FPIES reactions, is vomiting repeatedly, appears ashen-gray or lethargic, call 911 immediately. If you know your child ate their trigger food, you should head off to medical attention, such as an ER rather than a doctors office, so that monitoring and potential treatments can begin promptly. If prior reactions were mild (such as 1-2 episodes of vomiting) and self-limited and your child appears comfortable and is no longer vomiting, oral rehydration with clear fluids or ice chips at home may be sufficient, but always speak with your doctor. Wait 10-15 minutes after an episode of vomiting and start offering small amount e.g. 1 tsp-1tbs of clear liquids every 5 minutes. Do not offer larger volumes of fluid because they may provoke more vomiting.

What can I expect at the first allergist and/or gastroenterologist appointment?

Be prepared to be asked many questions from your specialist. Your answers to those questions are essential because the diagnosis of FPIES is what is called a 'clinical diagnosis'. This term, 'a clinical diagnosis', refers to conditions where there is no definitive laboratory tests to confirm or make a diagnosis. In these instances, the doctor depends on the child's medical history to decide what is going on. What the specialist needs to know (you may want to write this down in advance of the appointment!)-

1. What happened? What were the symptoms experienced by the child?
2. What was the time course of the child's symptoms? What foods were involved?
3. How old was the child at the time of the event(s)?
4. How many times has this happened? Was it the same every time?
5. What was the timing from the exposure to a suspected food to the onset of the child's symptoms?
6. What was done to take care of the child? How long did it take for the child to recover?
7. What advice were you given about handling future events?
8. What tests have been done? Other questions will be asked to help rule out those other medical conditions especially infection or food allergy. The selection of tests may depend on whether or not the child is currently having an acute episode or is currently well and has recovered from the event.

What medical professionals are important in monitoring my child's care plan?

In addition to continuing your relationship with your child's primary care provider, the assistance of a Board Certified Allergist-Immunologist and/or pediatric Gastroenterologist will help to ensure your child is avoiding the food associated with his/her reaction. In addition to obtaining a thorough history, these specialists may need to perform one or more food challenges.

Additional medical team members may include:

- A *Registered Dietitian* to assure that your child is receiving appropriate nutrition to reach his or her maximum growth potential and to provide education regarding safe dietary elimination.
- An *Occupational Therapist* or *Speech Therapist* may be necessary if your child requires feeding therapy secondary to an oral aversion he or she may have developed due to food restrictions.
- A *Social Worker* may provide direction and guidance obtaining coverage for medical expenses and medically necessary formulas. He/she can also point your family in the direction of an therapeutic services that may be needed.

What are the goals of long term management of FPIES?

- 1) To maintain proper nutrition
- 2) To obtain "safe" foods
- 3) To be ready to treat an accidental exposure that results in a reaction
- 4) To be monitored for possible resolution of the allergy with a goal to expand the diet if possible
- 5) To seek out a support system for the child as well as the family.

How do I safely provide foods for my child?

- *Learning to read ingredient labels* becomes an essential skill for families to safely prepare foods for a child with FPIES.
- *Mastering basic ingredient substitutions* and learning to modify familiar recipes can help to provide more dietary options
- *Learning your child's degree of sensitivity* and response to cross contaminants
- *When eating away from home*, consider doing research about the restaurant in advance and carrying allergy information cards when visiting the restaurant.
- *A registered dietitian may provide ideas* regarding avoidance of trigger foods and ensuring dietary needs are met.
- *When preparing to enroll your child in daycare or school settings*, you may consider:
 1. *Meeting with school professionals* to discuss your child's condition and degree of sensitivity.
 2. *Discussing with school professionals* the potential for food exposures throughout the day.
 3. *Drafting a formal plan* such as a 504 plan (based on your child's qualifications)
 4. *Preparing snacks and/or meals* with foods only from home.
 5. *Preparing an emergency plan* so that professionals know how to recognize an FPIES reaction in your child.