



International FPIES Association (I-FPIES)

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Date:

Child's Name:

Dear Educators,

The International FPIES Association (I-FPIES) is a non-profit organization for children and families affected by Food Protein-Induced Enterocolitis Syndrome (FPIES). We assist and support children and families diagnosed and affected by FPIES. Recently, _____ was enrolled in your school/daycare. We would like to provide some support and guidance by offering the following tips for managing the care of a FPIES child in your school setting.

Food Protein-Induced Enterocolitis Syndrome is a rare, often misunderstood syndrome. FPIES is a non-IgE allergy of the gastrointestinal system, which means that it does not produce typical allergic responses such as hives, swelling, difficulty breathing or anaphylaxis. Rather, this syndrome produces symptoms of profuse vomiting and/or recurrent, painful diarrhea, oftentimes filled with blood or mucous. Reactions are typically delayed two hours or more after consuming the offending food. Sometimes, a child may have such violent vomiting and/or diarrhea bouts that he/she may go into shock. This occurs in ~20% of cases. The use of epinephrine injections will not reverse the development of shock in these children.

You may say to yourself, "But this child looks so healthy and strong; they don't look ill." However, FPIES falls under the umbrella of "Hidden Disabilities" due to its allergic nature. FPIES children may appear just as other non-FPIES children do, but they often have numerous dietary restrictions. It is important to understand that FPIES is not contagious in any way. Often, FPIES will be misdiagnosed or present as a "stomach bug" or the flu, but symptoms only occur when a child ingests a food to which he/she is allergic.

Many children with FPIES have strict and very necessary dietary restrictions. We recommend that when a child with FPIES is enrolled at your school that you follow these guidelines to ensure the safety and comfort of the child, parents and educators:

Schedule a Meeting with the Child and Parents

Request an hour or so of the family's time and have the child's teachers and administrators be present. First, discuss your concerns and questions about the child's transition into your school. Review your current policies and procedures for children with medical conditions and food allergies. Understand that starting school for a FPIES child can be worrisome for the family.

Ask the family to provide a brief history of the child's diagnosis. Listen to their journey. This will help you to understand the challenges the child and family face on a daily basis and reduce the parents' concerns about their child attending school. I-FPIES highly recommends that you take detailed notes and ask questions.

Ask for Documentation and Post a List in the Child's Classroom

Have the family provide you with a list of the child's safe foods and trigger foods. Also, ask the family how the child's symptoms usually present and how they would like you to manage the child's care in the classroom. Some children react within two hours of the exposed food protein, others will react within several days or weeks of trying a new food. The family should explain in detail the "food trial" process and should advise you when they are trialing a new food at home with the child.

Work with the family to create a document to post in the classroom at all times, in case one of your educators is absent and a new substitute or caregiver is present. We recommend photocopying the child's picture, writing a brief description of FPIES underneath and then listing the child's safe foods and trigger foods. We also recommend that the parent keep this document current and encourage communication between both parties to maintain a safe learning environment.

Review an Emergency Plan

Families of children with FPIES should carry an ER letter with them at all times. If the family does not have an ER letter, I-FPIES lists one on our website at www.fpies.org. We recommend that the school also have a copy of this document. This letter explains the diagnosis in detail and helps new medical providers or emergency room staff to understand how to treat FPIES should there be an emergency.

Review with the family how they would like you to address emergent situations. Some families will prefer that you call 911 first, others will want you to contact them first. If a child goes into shock at school, always call 911 first. If a child accidentally ingests a food that he/she has never had before or is listed on his/her trigger list, call the parent immediately. Produce a formal "Emergency Plan" document with the family and have both parties sign and date this agreement. This will reduce worry on both ends and will help the family to feel confident in their child's educational team.

It's also important to note that some children may be hospitalized for a period of time to treat their severe reactions. Children often display behavioral changes after an admission. I-FPIES recommends discussing with the child's parent what behavioral changes the child may exhibit and how to address them appropriately. In addition, FPIES children may have regularly scheduled physician appointments and may have to miss school to attend these appointments.

** Additionally, some FPIES children may also have IgE allergies and symptoms (hives, swelling, difficulty breathing, anaphylaxis). Discuss any IgE allergies with the family. If the child requires the use of an Epi-Pen, review how to administer this with the child's parents.

Learn How to Prepare the Child's Food

Many children with FPIES require special diets. Some children only consume an elemental formula, which is a special medical formula that is safe for the child. Often, the formula must be prepared for the child when he/she would like to eat. Ask the family to provide you with an educational demonstration of how to prepare formulas, medical foods and how to avoid cross-contamination of foods. Take notes and demonstrate to the family that you understand how to prepare these items.

We recommend asking the parent to keep a backup supply of the child's safe foods in the classroom at all times. This way, should the child's supply run out, he/she will still be able to receive adequate nutrition and participate in mealtime in the school setting.

Discuss Holiday/Party Modifications to Include the Child

Holidays and parties can be especially difficult for children and families with FPIES. FPIES children often cannot eat the treats provided at parties, which can be quite upsetting. An understanding of this is so very important on the school's behalf. We suggest asking the child's parents to take an active role in planning for parties. Possibly suggest the role of "Class Mom or Dad" so that they will have some creative input into parties and be able to provide enjoyable substitutions for the child during parties and holidays. With planning and creativity, some foodless alternatives can be offered to the child (for example, crafts, art supplies, creativity with the child's safe foods). We also recommend the inclusion of the child in the party setting and awareness that the child may feel excluded or upset.

Maintain Open Communication with the Child and Family

Invite the family to discuss their concerns and any updates with you via phone, e-mail or in person. This reduces the family's worry and will also provide the school an opportunity to enhance your skills and resume. Children with FPIES want to be included and have normalcy in their lives. The diagnosis can be very difficult for both the child and family. A reciprocal, positive relationship with the child's school can serve as a strong support system for these families. We recommended regular, open communication between both parties.

If our organization can be of assistance to you in the future, please reach out to us at contact@fpies.org. You may also visit our website at www.fpies.org for more information about FPIES.

Respectfully,

The International FPIES Association