



Dear School or University Staff,

One of your students lives with a diagnosis of FPIES (Food Protein-Induced Enterocolitis Syndrome), an uncommon type of food allergy that affects the gastrointestinal tract. When your student ingests his/her/their “trigger” foods, it causes a delayed reaction 2+ hours after eating the offending food. Reactions can be severe, marked by profound vomiting, diarrhea, and often severe abdominal pain. In addition, the individual may feel very lethargic and experience a drop in blood pressure. Approximately 15-20% of FPIES reactions can progress to shock, a life-threatening medical condition.

An auto-injector of epinephrine will not stop an FPIES reaction; therefore, emergency medical attention may be required in the event of a severe reaction. Upon such time, the attending ED physicians will often treat the reaction with IV fluids and potentially steroids. There is no cure for FPIES and the only management strategy for affected individuals is avoidance of the implicated foods. In addition, it is possible for individuals to discover new trigger foods over time, just as an individual may discover new IgE-mediated food allergies. Because there are no available tests to determine which foods are safe or unsafe for an individual affected by FPIES, all new foods must be trialed, one single ingredient at a time. As a result, it may take some time for an individual to know which foods he/she/they are able to safely eat.

Please be receptive to any medical information regarding this condition that your student feels comfortable sharing with you (including food trigger lists) and please be respectful of his/her/their need for privacy regarding this medical condition.

Following an FPIES reaction, the affected individual may feel unwell for a day or more. Your student may find it helpful to work from home during this time period, have a reduced schedule, or have one or more sick days. Every individual is unique, so it is important to speak to your student about his/her/their specific needs related to living with FPIES. Having a plan in place to address potential missed school work due to an FPIES reaction can be helpful to establish at the beginning of the school term/semester. This plan could also be developed in conjunction with the student’s advisor.

Though it is impossible to guarantee that a reaction won’t ever happen in class, the likelihood of an FPIES reaction occurring (as a result of school activities) can be reduced with a few simple steps.

1. Foster team-building and community through non-food events, like drum circles, bowling, etc.
2. If there are communal eating events in class, posting ingredient lists for each of the foods offered can help an affected individual determine if he/she/they is able to eat the items provided.
3. Avoid buffet-style community eating events, as cross-contamination (i.e. when food proteins are transferred via utensils or other means to another food dish) between dishes can occur if someone accidentally places one food’s serving utensil in another dish.
4. If events will be occurring at restaurants or venues that will be catered, providing the affected individual with information about all ingredients contained in the dishes to be served can help him/her/them make safe decisions about what he/she/they plan to eat at the event.



5. FPIES reactions can be scary and cause a detrimental impact to an individual's quality of life--- *students may not want to eat any food that they do not prepare themselves*. Demonstrating an understanding for this sentiment and allowing individuals to bring their own food for food-centric events can greatly reduce potential anxiety for your student.
6. Allow your student notice about upcoming, food-centric events; this can help him/her/them plan ahead and have time to determine what options he/she/they feel most comfortable with
7. Present your student affected by FPIES (as well as other students affected by food allergic conditions) with the opportunity to help plan for or give input regarding future food-centric events.
8. Discourage and immediately address any bullying that may occur as a result of your student's dietary restrictions. FPIES is a type of food allergy, and food allergies are classified as disabilities, protected by federal law. All students deserve the right to work/study in an environment free of discrimination.
9. Ensure that his/her/their workspace/desk is clear of foods and is not used at other times of the day as a space for eating by others
10. Your student may have additional suggestions! We are sure you will be receptive to their insights, as they have experience living with FPIES!
11. As with other potential emergencies, be sure to have a plan in place for how to address a medical emergency that could occur due to an FPIES reaction. Work closely with your student and campus medical services so that you can best address his/her/their needs.

Thank you so much for taking the time to learn about FPIES and ways that you can help to support your student affected by this life-altering condition. If you require additional resources or simply have more generalized questions about FPIES, please connect with us at The FPIES Foundation.

Best Regards,  
Joy Meyer, DTR, and Amanda LeFew, MT-BC,  
Co-Directors and Co-Founders  
The FPIES Foundation  
[www.fpiesfoundation.org](http://www.fpiesfoundation.org)  
[www.fpiesday.com](http://www.fpiesday.com)  
[www.fpiesregistry.com](http://www.fpiesregistry.com)