

## Helping Families Manage Food Allergy in Schools

### Tips and Tools for the Allergist and Nonallergist

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#### The Growing Problem of Food Allergy

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Food allergy is a growing epidemic in the United States. The Centers for Disease Control and Prevention estimate that nearly 3 million children younger than 18 years are affected by food allergy; over the past 10 years, the number of new cases of food allergy has increased 10-fold.<sup>[1]</sup> Food allergy can have a wide-ranging, negative effect on children and their families, affecting not only life at home but also work, education, vacation, and entertainment. Virtually no life activity remains unaffected by the presence of a potentially fatal allergy.<sup>[2]</sup> Recognizing that there is no known cure or proven treatment, the number of cases of food allergy is expected to increase. Studies have also suggested that many food allergies persist longer than was once previously assumed.<sup>[3]</sup> The chances are high that an individual parent or child will interact with a food-allergic person every day. Although much work has been accomplished in spreading the message that food allergens can potentially be life-threatening, a clear lack of understanding about this issue in many persons *without* food allergy remains.<sup>[4]</sup> The main management strategy for food allergy -- avoidance -- is difficult to implement, a fact often underappreciated by unaffected individuals. Food allergy has become a global social issue, and protecting the health and self-esteem of affected children as well as the quality of life of the family, is a responsibility that must be shared by the entire community.

Sending a food-allergic child to school, camp, or child care can be a daunting task for a parent and may be associated with much anxiety. Increasingly, allergists and nonallergists are being asked to help prepare students and their families to make a safe transition. This involvement consists of ensuring the following:

- Each student has a self-injectable epinephrine device;
- The family and child (if age-appropriate) know how and when to use the device;
- The family can train others to use the device; and
- The student has an emergency action plan for the facility to follow in case of a reaction.

Often, more detailed involvement is requested in guiding classroom and/or facility-wide policies, such as the establishment of section 504 plans or other individualized health plans that afford protection and services for food-allergic children at school. Understanding real vs perceived risks of a potential food-induced reaction at school or child care can be helpful in planning.

Let's review the published evidence to gain a better understanding of this situation.

#### How Common Are Reactions at School?

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##### What Are the Chances That a Reaction Will Occur at School or a Child Care Center?

Reactions do occur at school and can be severe under certain circumstances; however, their overall occurrence is still rare. There are no exact data detailing how often reactions occur in school.<sup>[5]</sup> One study found that they occurred more frequently in younger children, particularly those in preschool and kindergarten.<sup>[6]</sup> The reasons for this are not entirely clear, although a contributing factor may be that food allergy commonly first presents at that age, and therefore some initial reactions may occur in the school or child care setting. Another potential contributor is that common allergenic foods (eg, peanut butter) may be used in class projects, which increases the potential for exposure. In addition, older children may be more experienced and better trained in knowing what they can and cannot eat, explaining the lower rate of reactions in the older age range.

Sadly, there is a growing trend among some parents to "home-school" their food-allergic children out of fear that their child is at high risk for a reaction that will not receive adequate protection at school. This misperception diminishes quality of life for these families. There are no data to support the need for home-schooling to provide protection and decrease risk.<sup>[5]</sup> It is important to understand that the vast majority of even severely food-allergic children can and *do* attend school safely every day, and there seems to be little risk in attending school for food-allergic children.<sup>[5-7]</sup>

## What Route (eg, Oral, Contact, Inhalation) Is Most Likely to Cause a Reaction at School or Child Care?

The highest risk for any food-induced reaction stems from direct ingestion of the food. Moreover, the risk for a severe allergic reaction from an unintended environmental exposure, such as contact with a contaminated surface or inhalation of air-borne particles, seems to be extremely low. Unfortunately, a common misperception held by many persons in the food-allergic community is that these are realistic risks. This belief causes unnecessary alarm and anxiety and may lead to requests for unwarranted precautions to be taken at school or child care, or may influence the decision to home-school.<sup>[8,9]</sup> However, the evidence to the contrary is quite clear.

Peanut and tree nut particles are commonly believed to have the potential to provoke a reaction from air-borne inhalation.<sup>[5,6,10]</sup> In a study from Johns Hopkins, researchers failed to detect measurable quantities of peanut in air filters around the necks of volunteers who danced on peanut shells scattered on the floor of a poorly ventilated room.<sup>[8]</sup> Similarly, in a study from Mount Sinai, blinded participants inhaling from a jar of peanut butter at very close range did not experience significant allergic reactions from the exposure.<sup>[9]</sup> This same study also did not find detectable levels of peanut on surfaces first smeared with peanut butter then cleaned with commercial products. Detectable levels were also not found on hands coated with peanut butter and then washed with soap and water, nor after cleaning with liquid hand sanitizer.

Skin contact as a route of exposure may be of particular concern in younger children who are more prone to touch contaminated items and not wash their hands before placing them in their -- or someone else's -- mouth. This is why a policy supporting strict handwashing after food contact in young children is important (to prevent both allergic reactions and infections). Nonetheless, these children still need to ingest the food to cause severe symptoms, although cases of contact urticaria can occur from certain foods in allergic children. Contact urticaria is generally self-limited to a cutaneous reaction that causes some mild discomfort without further generalization to other organ systems.<sup>[11]</sup> Wiping down the skin area of allergen contact often resolves the reaction. However, contact urticaria could be misinterpreted by a frightened observer unfamiliar with the child's reaction history as a sign of a more severe reaction.

Inhalation reactions are frequently reported anecdotally, although again, evidence to support this as a reaction-inducing mechanism is limited.<sup>[6-9]</sup> What most likely occurs in these cases is that dust or particles are briefly released into the air but settle quickly, and unnoticed contact between the skin -- and subsequently the oral mucosa -- and the now-contaminated surface occurs, introducing unrecognized ingestion. (For example, a hand might touch a contaminated counter, and then is brought to the mouth.) Alternatively, anxiety in this situation may induce subjective symptoms like wheezing or shortness of breath attributable to paradoxical motion of the vocal cords, pharyngeal tightening, a globus sensation, itching, and even urticaria.

To summarize a point that is often misperceived: The greatest risk for a reaction at school or child care in a food-allergic child is from direct ingestion of the allergen and not from other routes of exposure. This is essential to keep in mind when making any classroom or facility recommendations.

## Management of Reactions at School

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### How Should Reactions That Occur at School or Child Care Be Managed?

Food-allergy reactions, irrespective of the particular location in which they may occur, should be treated in a universal fashion.<sup>[12]</sup> Isolated cutaneous or mild gastrointestinal symptoms without any signs of shock; hypotension; or laryngeal, pharyngeal, or lower respiratory symptoms can generally be managed with short-acting, oral H<sub>1</sub>-antihistamines. Examples of such agents include diphenhydramine (Benadryl<sup>®</sup>) and hydroxyzine (Atarax, Vistaril<sup>®</sup>). If available, an oral H<sub>2</sub>-antihistamine like ranitidine (Zantac<sup>®</sup>) or famotidine (Pepcid<sup>®</sup>) should also be added because combined activation of the H<sub>1</sub>- and H<sub>2</sub>-receptors can facilitate cardiovascular collapse and coronary artery vasospasm.<sup>[13]</sup>

Epinephrine should be administered as soon as possible for more severe symptoms involving laryngeal, pharyngeal, or lower respiratory symptoms; abdominal colic or protracted vomiting; and/or evidence of shock, hypotension, or circulatory collapse, followed by administration of H<sub>1</sub>- and H<sub>2</sub>-antihistamines with additional rounds of epinephrine as necessary.

Anaphylaxis should *always* be treated with epinephrine as soon as recognized. [Guidelines](#) describing the symptoms that constitute anaphylaxis and recommendations on medication use at specific points in treatment have been jointly published by the National Institutes of Allergy and Infectious Diseases and the American College of Emergency Physicians.<sup>[12,13]</sup>

Previous research has suggested that proper treatment is sometimes delayed and that the wrong treatment is sometimes

used for children experiencing reactions at school or child care. One study noted significant delay in children receiving epinephrine; moreover, many children in this study received diphenhydramine or some other medication in lieu of epinephrine, despite the indication for epinephrine (based on the reported symptoms).<sup>[6]</sup> Studies of reactions in other venues have also highlighted the same issues regarding epinephrine underutilization.<sup>[13]</sup>

There is evidence that emergency action plans are not always followed as written and that many food-allergic students do not have an emergency action plan or emergency medication (such as epinephrine) at school.<sup>[6]</sup>

Furthermore, full-time nursing availability in school is becoming uncommon, which places the burden of assessment and treatment of reactions on teachers or administrators, many of whom are unqualified or only minimally qualified for these tasks. The confluence of these issues can create a “perfect storm” resulting in a student not receiving appropriate treatment promptly. Nursing issues in school are an unfortunate present (and likely future) reality, with budget cutbacks requiring that nurses be shared by several facilities. Some private child care centers or private schools elect to go without a nurse. In frustrating contrast, it has been shown that students attending schools and child care centers with full-time nursing were significantly more likely to maintain self-injectable epinephrine and (in the event of a reaction) have their action plans followed.<sup>[6]</sup>

To summarize, both the school and the food-allergic family are often not prepared to treat reactions. The healthcare community must seize the opportunity to do a better job in educating all involved.

## School Policies and Strategies

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### What Are Some Examples of Effective Strategies and Policies for the Classroom of Child Care Center?

Very often, the healthcare provider caring for the food-allergic child is placed in a position to make recommendations to the school or child care center that have potential policy implications that affect not only the patient but also the other children in the classroom. Unfortunately, there is a lack of established evidence to support many of the recommendations. Instead, “expert opinion” of the allergist or treating clinician is relied on, and this is highly problematic because many providers are not familiar with the evidence or properly trained to make such recommendations (this applies to both allergists and nonallergists).

Specific examples of commonly recommended policies include the following:

- Make a classroom or facility allergen-free (eg, “nut-free” or peanut-free);
- Require handwashing after food contact;
- Use special tables with certain food restrictions (eg, “nut” or peanut-free tables);
- Place restrictions on sharing of food;
- Restrict use of food items for school projects and celebrations; and
- Establish policies that isolate the food-allergic child to a separate area of the facility at mealtime.

Despite widespread use of such policies, there is little if any established evidence to support their efficacy.<sup>[4]</sup> This is particularly the case for making a classroom or facility allergen-free (which is typically done for peanuts and/or tree nuts). Although schools sometimes have policies on peanuts or tree nuts, 1 study found that, despite such measures, more than 19% reported that a reaction still occurred at the facility.<sup>[6]</sup> This highlights single-allergen exclusion strategies as both potentially ineffective due to lack of enforcement and a contributor to a false sense of security. Furthermore, this strategy can be a point of contention between parents of food-allergic and non-food-allergic children.

Although evidence for the effectiveness of such strategies as handwashing, cleaning common surfaces, not sharing food, not using food for class projects or celebrations, and making separate seating available in the eating area is debatable or lacking, they are generally viewed as less contentious and have little effect on the lives of unaffected students.<sup>[4]</sup>

In general, when asked to intervene and make school or child care recommendations, it is highly advisable to place the least amount of restriction as possible on other children while offering adequate protection for the allergic child. Requests are often parent-specific and based on the parents' perception of need and familiarity with the facility. Some parents do not know what to ask for and thus it is incumbent on the professional to be familiar with the evidence.

Parents should be encouraged to meet with the school or facility and, if necessary, school district officials to explore their particular situation. A “1-size-fits-all” strategy, such as a state guideline, may not be available or appropriate. For example, restrictions for small children may be unnecessary for older children. Parents should also be encouraged to attempt to

reach out to other parents in the classroom to help facilitate cooperation.

At present, 13 states (Arizona, Connecticut, Illinois, Maryland, Massachusetts, Mississippi, Missouri, New Jersey, New York, Tennessee, Vermont, Washington, and West Virginia) have centralized guidelines for managing food-allergic students, making the process easier for everyone involved. (Texas and Pennsylvania also recently approved measures, but a bill for these measures was rejected in Florida).<sup>[14]</sup> Guidelines serve to unify the approach to management and provide the legal basis of a mandate for particular accommodations.

## Special Circumstances in Advising Families With Food-Allergic Members

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Although there are many potential examples, the following 3 issues merit special attention.

### What Risks Do Teenagers and Young Adults Face in Managing Their Food Allergy?

Older children with food allergy, specifically teenagers and young adults, face somewhat different issues. Fear of exposure from craft projects or poor hand hygiene are generally not issues at this age. Most of these children are old enough to ask about potential contamination or communicate that they have a food allergy, although they do not always do so. Limited study of this age group has highlighted that, unfortunately, risk-taking behavior is common.<sup>[15-17]</sup>

Published registry studies have documented that the vast majority of fatal food reactions occurs in this population of food-allergic individuals, including on college campuses.<sup>[17,18]</sup> This finding is disconcerting. Intentional risk-taking in college students is manifested in a variety of ways, including the following:

- Not maintaining emergency medication to treat a potential reaction (including self-injectable epinephrine);
- Poor notification of close friends and contacts (including health services and dining services) of a food allergy; and
- An increased willingness among those who have never had an anaphylactic or severe reaction previously to intentionally ingest a known allergen.<sup>[17]</sup>

Identified fatalities from a 2-part study of a longitudinal registry showed a clear association with people who either did not have their epinephrine device or receipt of the drug was delayed.<sup>[15,16]</sup> Limited focused study of food-allergic teenagers has revealed that peer pressure, a need to “fit in” with the other kids, and bullying were all associated with risk-taking.<sup>[18,19]</sup>

### What About Reports of Bullying of Children With Food Allergies?

Bullying students with food allergy occurs and can take both verbal and physical forms.<sup>[19]</sup> Survey studies and observations commonly note teasing, taunting, and harassing children who are food-allergic. In March 2011, the story of a 6-year-old peanut-allergic girl in Edgewater, Florida, was a prime example of bullying at the community level.<sup>[20]</sup> Based on news reports, unaffected students were subjected to draconian measures and there was a community-wide protest of the food-allergic child's right to attend public school.<sup>[20]</sup>

A recent study of 353 teenagers found that 24% reported being subjected to some form of bullying and that 80% experienced multiple episodes.<sup>[19]</sup> The vast majority of teens in this report considered the bullying to be directly related to their food allergy, and some reported that they were intentionally exposed to their allergen. Emotional consequences of bullying, including depression, sadness, and embarrassment or humiliation, were reported by 67 of the children in this study.<sup>[19]</sup>

These are rather serious findings, and bullying and similar behaviors in schools are probably underreported. No child should feel unsafe in their learning environment or feel persecuted or singled out because of a medical condition. When caring for food-allergic patients, it is critical to ask about bullying and emotional well-being as part of routine office visits.

### What Protections Does the Americans with Disabilities Act Afford a Food-Allergic Child?

The following 3 laws are often referenced when protection for a food-allergic child is being discussed:

- [The Rehabilitation Act, section 504](#)
- [The Americans With Disabilities Act \(ADA\)](#) and
- [The Individuals with Disabilities in Educational Act \(IDEA\)](#).

All 3 laws delineate rights for disabled individuals -- the most applicable to the right to educational accommodations for food-allergic children attending facilities receiving public funding is section 504 of the Rehabilitation Act. This section

affords children with disability equal rights to services at school and stipulates that "no qualified individual with a disability in the United States shall be excluded from, denied the benefits of, or be subjected to discrimination under any program or activity that either receives federal financial assistance or is conducted by any executive agency or the United States Postal Service." To be afforded these services, the individual must be considered disabled as defined by specific criteria under the ADA. The ADA applies to most schools regardless of funding sources (eg, public and private schools). Food allergy is not covered by the IDEA unless the child has another need for special education. Schools do not have to provide Individualized Educational Plans as they would under the IDEA. Individualized Educational Plans are often confused with Individualized Health Plans (IHPs), which do result from enforcement of the Rehabilitation Act. The alphabet soup of regulatory acts can be quite intimidating.<sup>[21,22]</sup>

Let's clarify this a bit more. A typical situation occurs when parents wish for formalized accommodations for their food-allergic child at a public school or private school receiving some public funding. Their options are to try to work out some accommodation with the school, obtain an IHP from their healthcare provider, or obtain a section 504 plan. The IHP is formulated in conjunction with the school nurse, parent, and healthcare provider. It serves as a guide for how to protect the child in the school setting, typically outlining risk-reduction strategies and medication use, as described in the previous section. Many providers choose to write form letters that serve as informal IHPs, but formal versions exist. An official section 504 plan is similar to an IHP, except that the 504 plan is written on an official document and comes with the right to legal representation and "due process" to enforce the rights laid out in the plan.

To obtain a plan, the child must be formally evaluated under section 504 to determine whether he or she meets the ADA definition of a disability, which is defined as a "physical or mental impairment which substantially limits one or more major life activities." "Major life activity" includes "walking, seeing, hearing, speaking, breathing, learning and working" as well as "eating". Thus, a food allergy *could* be a covered condition, but determination of disability is subject to a formal evaluation by the school district. Districts are required by law to have a designated 504 Coordinator to ensure that the provisions are enforced. However, it is *imperative to understand that the legal system has not always upheld the view that a food allergy (even a severe allergy) is a disability*. In fact, 11 appellate-level cases have upheld a ruling that a food allergy was not considered a disability.<sup>[22]</sup> Therefore, it is very important to document the nature and extent of the child's food allergy so this information is available when the case is reviewed. Unfortunately, there is a common misperception that children with food allergy automatically qualify as having a disability. The passage of the [Americans with Disabilities Act Amendments Act of 2008](#) extended the reach of the ADA with the intent to lower the threshold to qualify as having a disability due to food allergy.<sup>[22]</sup>

Children who are granted a 504 plan are then afforded the right to a "free and appropriate education" by the school district (this includes all public schools and any private school receiving federal funding) equal to that provided to nondisabled students, although if the efforts to provide this education are believed to cause an "undue burden," the school district does not have to provide that level of services. This stipulation is complex, however, and a thorough discussion is beyond the scope of this article. Many clinicians, while amenable to helping families obtain a 504 plan, may choose to deal with the school or child care center on a less formal basis and only resort to a formal plan if special circumstances arise, such as inability or unwillingness to enforce accommodations. However, it is important to have a written, documented plan -- regardless of the type -- and to engage the parents of the child to learn the specifics of their situation and help them decide if a formalized 504 plan is needed. The Food Allergy & Anaphylaxis Network provides a downloadable [parent guide](#) for kids with food allergies that explains these varying protections

## A Summary of Legal Protections for Children With Food Allergy

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The following discussion is a quick-and-dirty primer of the legal protections for children with food allergy. The take-home message is 2-fold:

- A section 504 plan is part of the Rehabilitation Act and not the ADA. However, to obtain a 504 plan a child must be considered disabled under standards defined in the ADA.
- Although food allergy has been considered a disability under the ADA in many cases, having a food allergy does not automatically imbue disability status. It should be kept in mind that *food-allergic children are not necessarily entitled to qualify as disabled*. Children who can obtain a section 504 plan are entitled to legal protection to enforce the plan. Accurate and precise documentation of the extent of the allergy is crucial to helping with this process.

## Conclusion

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This discussion has reviewed some of the considerations that clinicians (allergist or nonallergist) should remember when advising the food-allergic family about attending school or child care.

Following are some important summary points to consider in counseling food-allergic patients in your practice.

**Kids with food allergy, even severe food allergy, can and do safely attend school every day.** This is the goal that we all must work to achieve through effective school policies as well as community and school education.

**Food allergic students of every age *must* be provided with a current emergency action plan that is updated each year, and keep epinephrine at school.** Providers must strongly encourage parents to make sure that the school or child care center has both the plan and the emergency medication in its possession and knows how to use the drug in the event of an emergency. Parents should take the initiative to ensure that the center or school can execute the steps of the action plan. If necessary, parents must also take the responsibility to train staff in recognizing a reaction and using self-injectable epinephrine. Clinicians must ensure that parents of food-allergic children have been trained to do this and must be available to help schools and centers in need of training.

**Restrictive policies that are not backed with evidence of need and efficacy (eg, allergen-detecting animals, forced washing of the face and rinsing the mouth before entering the classroom) should not be encouraged.** However, strategies like handwashing after food contact, not sharing food, and being aware of children's dietary restrictions when planning craft projects or class celebrations are effective and minimally disruptive to both the food-allergic child and unaffected children.

**The frustration that may be expressed by parents of unaffected children should not be dismissed by those who are affected by food allergy, just as the fear and anxiety that may be experienced by the family of those with food allergies also need to be taken into account by those who are unaffected.** This is not a "zero-sum" game, and both sides have the right to express their feelings as long as the dialogue fosters a productive debate that leads to a mutually satisfactory solution.

**Efforts should be focused on common-sense approaches stressing empathy, understanding, and a sense of a communal effort to protect students both with and without food allergy.** It is important for school communities to work aggressively to reach a compromise that allows children just to be children and to attend school normally. Both allergists and nonallergists need to be strong community advocates for their food-allergic patients and help to facilitate this process.

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