# **A Caregiver's Guide**

# Providing Care for Children with Food Allergies

- Food Allergy FAACTs
- Anaphylaxis & Epinephrine
- Impact on Daily Activities
- Preparing for Care
- Advocacy & Awareness

# **#KnowTheFAACTs about Food Allergies**





## What is a food allergy?

An immune system response to a food the body mistakenly believes is harmful. Food allergies can be fatal. There is NO CURE for food allergies.

A severe reaction that is rapid in onset and may cause death. What is Anaphylaxis? (an-a-fi-LAK-sis)

Are food allergies the same as dietary restrictions?

No. There are food related conditions & diseases that are often confused with a food allergy. It's important to understand the child's specific needs.

It's a document that is signed by a medical doctor describing the child's specific medical needs. What is an Allergy & Anaphylaxis Emergency Plan?

What are some important safety measures?

Strict avoidance of allergen and prompt treatment of accidental ingestions (following child's allergy & anaphylaxis emergency plan.) Recent research tells us that today in the United States, food allergies affect **1 in 13** children

## ... that's 6 million children under 18 years of age

50% increase among children aged 0-17 (from 1997-2011)

Food allergies & asthma in children= **29%** - higher risk for anaphylaxis

**30%** of allergic children allergic to multiple foods

**90%** of food allergic reactions in the US are caused by **9 foods:** 



milkwheatcrustacean shellfishtree-nutseggfishpeanutssoysesame

However, any food can cause an allergic reaction

# **Anaphylaxis FAACTs**

Anaphylaxis (an-a-fi-LAK-sis) is a serious allergic reaction that comes on quickly and has the potential to become life-threatening.

Symptoms of anaphylaxis can develop rapidly after exposure to an allergen

- Can be fatal if not treated promptly
- Can include a wide range of signs & symptoms
- Symptoms can occur alone or in combination
- Requires immediate treatment

(Follow child's allergy & anaphylaxis emergency plan)

- Administration of epinephrine
- 911
- Observation in ER 2-24 hrs recommended
- Anaphylaxis caused by a food can occur within **minutes** to several hours after food digestion.
- Death to food-induced anaphylaxis may occur within **30 minutes to 2** hours of exposure.
- **Biphasic Anaphylaxis** is the recurrence of symptoms within 1-72 hours after initial symptoms have resided, typically occurring within >8 hours after the initial reaction.
- Approximately 20% of anaphylactic reactions recur within 4-6 hrs. (biphasic reaction)

# Strict avoidance is key!

## SIGNS AND SYMPTOMS OF ANAPHYLAXIS

Anaphylaxis (an-a-fi-LAK-sis) is a serious allergic reaction that comes on quickly and has the potential to become life-threatening. The most common anaphylactic reactions are to foods, venom, medications, and latex.

### Anaphylaxis signs and symptoms that may occur alone (\*) or in any combination after exposure to an allergen include:



### \* IMMEDIATE & POTENTIAL LIFE-THREATENING SYMPTOMS

Consult with a board-certified allergist for an accurate diagnosis and management plan.

Although the majority of individuals experiencing anaphylaxis have skin symptoms, some of the most severe cases have no rash, hives, swelling

EPINEPHRINE is the first-line of treatment for anaphylaxis

Antihistamines, inhalers, & other treatments should only be used as secondary treatment

ALWAYS CARRY TWO (2) epinephrine products at all times

Food Allergy & Anaphylaxis Connection Team AWARENESS • ADVOCACY • EDUCATION

FoodAllergyAwareness.org

The Voice of Food Allergy Awareness

When you, or someone you know, begin to experience symptoms, CALL 9-1-1 IMMEDIATELY!

# **Epinephrine FAACTs**

Epinephrine IS the **FIRST** line of treatment for anaphylaxis

**Epinephrine** (ep•uh•NEPH•rin) is a form of adrenaline- a hormone the human body creates naturally in response to stress. When administered epinephrine works rapidly to constrict blood vessels, which helps increase blood pressure and keep blood flowing to vital organs. Anaphylaxis can cause a severe and life-threatening drop in blood pressure.

It also relaxes airways to improve breathing, relieves cramping in the gastrointestinal tract, decreases swelling, and helps block itching and hives. It is important to be deliberate and not hesitate when you have to use epinephrine. The device is potentially life-saving and has far more benefit than risk.

- Early use of epinephrine to treat anaphylaxis improves a person's chance of survival and quick recovery.
- Antihistamines (i.e. Benadryl) **will not stop** the progression of symptoms in an anaphylactic reaction.
- Effects are not long lasting, additional doses may be needed.
- There are no contradictions to giving epinephrine.
- Make sure you are trained on epinephrine administration.
- Administer epinephrine = call 911.

## See next page for your Epinephrine Options.

## Do You Know Your Epinephrine Options? Available in the U.S. by prescription

**Auvi-Q** by Kaléo **Website:** auvi-g.com/

Available through Home Delivery and At Walgreens:

auvi-q.com/get-auvi-q/ Dosage: 0.1mg/0.15mg/0.3mg Hold time: 2 seconds Needle: Retracts after injection Trainer: Included Support Program: auvi-q.com/support

Training Videos: auvi-q.com/training



Epi-Pen and Epi-Pen Jr by Mylan Website: epipen.com/en/ Dosage: 0.15mg/0.3mg Hold time: 3 seconds Needle: Covered after injection Trainer: Included Savings Program: epipen.com/paying-forepipen-and-generic#PatientAssistanceProgram-

Administration Training Video: <u>epipen.com/en/</u> <u>about-epipen-and-generic/how-to-use-epipen</u>





#### **The Authorized Generic for Adrenaclick** by Impax **Available in CVS Pharmacy:** cvs.com/content/epipen-alternative

**Dosage:** 0.15mg/0.3mg **Hold time:** 10 seconds

Needle: Not covered after injection Trainer: Not included Savings Program: https://sservices.

trialcard.com/Coupon/Epinephrine

### Administration Training Video:

epinephrineautoinject.com/epinephrine-side-effects/how-to-use/



Neffy by ARS Pharma Website: neffy.com Dosage: 2 mg Weight: for individuals 66 pounds or more How to Use: neffy.com/#how-to-use and ars-pharma.com/wp-content/uploads/pdf/Instructions\_For\_Use.pdf How to Use in Adults: https://youtu.be/DnJlyHs1-sw How to Use in Adolescents: https://youtu.be/vyTM\_xRiJlk Savings & Support: neffy.com/#savings-and-support Neffy Action Plan: neffy.com/static/Action-Plan.pdf



### The Authorized Generic to Epi-Pen and Epi-Pen Jr

Website: <a href="mailto:epipen.com/en/about-epipen-and-generic/what-is-an-authorized-generic">epipen.com/en/about-epipen-and-generic/</a> what-is-an-authorized-generic

Dosage: 0.15mg/0.3mg Hold time: 3 seconds Needle: Covered after injection Trainer: Included Savings Program: <u>activatethecard.com/mygener-</u> iceai/?\_ga=1.45028076.935859954.1485174656 Administration Training Video: <u>epipen.com/en/</u> about-epipen-and-generic/how-to-use-epipen



#### Teva Epinephrine by Teva Website: tevaepinephrine.com

Dosage: 0.15mg/0.3mg Hold time: 3 seconds Needle: Covered after injection Trainer: Included Savings Program: tevaepinephrine.com/savings

Administration Training Video: tevaepinephrine.com/howtouse



For more information on epinephrine & anaphylaxis, visit: FoodAllergyAwareness.org



# **Impacts of Food Allergies**

In surveys of parents or caregivers of children with food allergies.

- **60%** reported that food allergies significantly affected meal preparation.
- **49%** or more indicated that food allergies affected family social activities.
- **41%** reported a significant impact on their stress levels.
- **34%** reported that food allergy had an impact on the child's school attendance.
- **10%** choose to home-school their children because of food allergies.
- 50% or more indicated that food allergies significantly affected their family social activities.
- 58% thought that food allergy affected their child's "playing at friends' house".
- 53-70% reported that activities such as birthday parties and sleepovers were significantly affected by food allergies.
- **59%** reported that school field trips were affected by food allergies.
- **68%** reported school parties were affected by food allergies.

## What is Bullying?

Unwanted, aggressive behavior that involves a real or perceived power imbalance. The behavior is repeated, or has the potential to be repeated, over time. Includes making threats, spreading rumors, attacking someone physically or verbally, and excluding someone from a group on purpose. [1]

Although most bullying reported by children happens at school, it also occurs other places children are together, including playgrounds, school buses, at home or in a friend's home, restaurants, camp and on the Internet.[2] In some cases, the school bully is not a student but a **teacher or other adult.**[3]

Bullying a child with a food allergy can range from taunting the child to physically assaulting with the allergen. It is considered a form of "disability harassment".

# Food Allergies can be Fatal



"Sabrina ordered fries again in the school cafeteria like the week before, which were safe for her then - making sure that they were cooked in vegetable rather than peanut oil. In the class after lunch, Sabrina began to wheeze. Thinking she was having an asthma attack, the teen headed for the school office at the other end of the building. By the time she got there, Sabrina was in serious respiratory trouble, and kept repeating "it's my asthma."

A teacher raced to Sabrina's locker to get her EpiPen auto-injector in case it was in fact her food allergies; school officials called an ambulance. Sabrina collapsed and lost consciousness, going into cardiac arrest before the device could be administered, before the ambulance arrived. Sabrina's heart was restarted at the local hospital, and she was airlifted to the Children's Hospital. Sabrina's heart and lungs were strong, but she'd suffered significant brain damage. Later, it would be determined that her devastated condition was the result of anaphylaxis due to food allergy. The coroner stated that the allergic trigger was dairy protein, which Sabrina would have been exposed to through cross-contamination from tongs used to lift her fries. Those same tongs had also been used to serve orders accompanied by poutine, the French Canadian accompaniment of gravy and melted cheese curds. She would have been allergic to the curds. On September 30, a day after her reaction, Sabrina was removed from life support and died.

Source: http://allergicliving.com/2010/07/02/sabrinas-law-the-girl-and-the-allergy-law

In cases of fatalities from food allergy in the school setting, fatalities were associated with significant delays in administering epinephrine.

Dec 17, 2010 -- One class of Chicago seventh-graders decided to have a party in class by ordering Chinese food. Katelyn was allergic to peanuts, and apparently reacted to peanut protein in her food. She was rushed to a hospital but ultimately died from the trauma. Medical Examiner says she died of anaphylaxis, a severe reaction to a food allergy.

Source: http://chicago.cbslocal.com/2010/12/21/7th-grader-dies-after-eating-school-party-food



"On April 13th, 2006 Emily died from anaphylaxis after eating a sandwich at a local restaurant. Emily was allergic to peanuts and she was very vigilant about reading labels and quizzing waiters and waitresses about her food. That day, a hidden trace amount of peanut cross-contaminated her sandwich. Ten minutes after eating the sandwich she started experiencing asthma like symptoms which rapidly turned for the worse as many body systems became involved in the allergic reaction. Twenty to twenty-five minutes after eating, Emily passed away. The reaction was rapid and overwhelming."



Source: http://www.foodallergyangel.com



"BJ Hom, age 18, died on the first day of a family vacation in 2008 after eating a dessert that contained traces of peanuts. The family was visiting a resort in Los Cabos, Mexico, to celebrate BJ's 18th birthday and his graduation from high school. BJ did not have an epinephrine auto-injector with him because his doctors thought his symptoms would always be mild that they never prescribed auto-injectable epinephrine."

Source: http://www.FoodAllergyAwareness.org/about/board\_of\_directors-2

## Quebec waiter arrested after seafood puts allergic customer in coma

Melissa Fundira CBC News August 4, 2016 Police considering laying criminal negligence charge toward waiter. The waiter could be charged with criminal negligence. According to the complaint, on May 29, Canuel ordered a beef tartare and alerted the waiter that he was allergic to salmon and seafood, said Sherbrooke police Const. Martin Carrier. "At the time of the order, the waiter took no notes and never went tot he kitchen to talk to the staff," Carrier said. When the meal arrived, an unsuspecting Canuel took a bite of his food. He soon realized he wasn't eating beef and informed his partner, who is a resident doctor.

If restaurant staff does not seem genuinely concerned about working with you to accommodate your needs, or if they appear to have little knowledge of food allergies, it's best to seek another dining option.

# **Preparing for Care**

Food Allergies are **entirely manageable**. They DO require attention to detail and vigilance, and certain foods will have to come out of the diet.

Learn as much as you can about food allergy, reaction prevention strategies, and how to protect the child.

## **LEARNING ABOUT FOOD ALLERGIES**

- Read articles, books, on-line reports, medical journals, visit FAACT's website: FoodAllergyAwareness.org.
- Learn as much as possible about the causes and effects of food allergies.
- Listen closely to what your grandchildren are saying about how food allergies affect their day to day lives and how they are dealing with it.
- Read case histories of a reaction to gain insight and understanding to potential severity.
- Offer to attend the child's doctor visit to help understand the severity of the food allergy.

When it comes to food allergies, strict avoidance of the food is the only way to prevent an allergic reaction. To ensure foods are safe for your needs, reading food labels is a requirement.

### **READING FOOD LABELS**

- Read EVERY label EVERY time before eating any food product.
- Ingredients & manufacturing can change over time. or may vary depending upon the size of the product (e.g.jumbo vs snack size).
- If a product does not have a label, it should not be eaten.
- Read labels on other products too! This includes all food, pet. beauty & craft items (i.e. clay & paste)
- Know the names of the allergen, including any other forms of the name it might be called)

What is the Food Allergen Labeling and Consumer Protection Act (FALCPA)?

Identifies nine major allergens in the U.S.: milk, egg, fish, (e.g., bass, flounder, or cod), Crustacean shellfish (e.g., crab, lobster, or shrimp), tree nuts (e.g., almonds, pecans, or walnuts), wheat, peanuts, soybeans, and sesame. FALCPA requires that major allergens be declared, in plain English, on ingredient labels. As of January 1, 2023, FALCPA requires sesame, the ninth major food allergen, to be declared on ingredient labels. Statements advising that products may/might contain or are made in shared facilities with a food allergen are purely voluntary.

If you have any concerns on the safety of a product, be sure to call the company to inquire about how their products are **processed**, their **cleaning methods**, and how items are **packaged**.

## Tips for finding items you can safely offer the child:

- Ask parents for a list of "safe" items they use.
- Seek out products in a "dedicated" facility that's free from the allergen.
- Call manufacturer if the label is not clear about the item's safety.
- Double-check products and labels with the parents to help ensure safety.

If the child visits your home, have "Safe Snacks" on hand, so you'll always have something safe they can eat.

### **TIPS FOR COOKING**

- Customize meals for safety AND food preferences.
- Modify recipes using allergen substitutes.
- Practice modifying recipes to avoid the child's allergen; taste test the recipe.
- When preparing food for a child with allergies, always use separate utensils.
- Read all labels to be sure products is allergen-free and there is no cross-contact.

### **TIPS FOR CLEANING**

- Sweep and mop floors.
- Wipe down kitchen counters with Clorox wipes.
- Vacuum rugs, furniture and behind furniture (crumbs love to "nest" in the cushions).
- Clean any other areas or items you think could be problematic.

# Remove all products that contain the child's allergen from the home OR: Organize food

- Pantry- keep safe foods together located on same shelf.
- Refrigerator- designate a shelf for allergen-free foods.
- Use color coded containers for food storage- let the child pick the color they'd like.

(Eat only in the kitchen- if snack while watching TV, make it safe food!)

## WHAT IS CROSS-CONTACT?

**Cross-contact** can occur through incidental contact with utensils, pots and pans, and preparation surfaces. The good news is that allergens can be readily cleaned from hands and body parts, cookware and utensils, and environmental surfaces.

### Hands YES 🔗

Soap and water

YES 🔗 Hand wipes (Wet Ones/Tidy Tykes)

NO 🔀 Plain water

NO 🔀 Plain water

## Surfaces

### YES 📀

- Lysol sanitizing wipes
- Formula 409
- Commercial cleaning wipes
- Target brand cleaner with bleach
- Other common household cleaning agents

**NO** 🔀 Liquid dish soap

# **Dining Out Tips**

- Before dining out, check the restaurant's website to determine if there are potential safe foods and whether ingredients are listed on the menu. Ask to speak to a manager or chef in advance to discuss your concerns.
- When seated at a table, use a commercial-detergent- containing wipe to wipe down the eating area and chair that the food-allergic individual may come in contact with. If menus are re-usable, wipe these down as well before allowing the food-allergic individual to touch them.
- ALWAYS bring written instruction cards that include your grandchild's allergens, and ask to speak with the chef or manager (even if you spoke to them in advance). Specifically ask for separate utensils, pots/pans, plates, and preparation surfaces that have not come in contact with the allergen(s) in question.
- If an item is served that you know or suspect contains the allergen in question, ask for a separate dish to be brought out and HOLD ON TO YOUR DISH until a new one is prepared. Never allow the item to be brushed off, picked out, or "eaten around" since allergens can easily rub off and contaminate the dish even after the item has been picked off or brushed off.
- Even if you have eaten at a particular establishment before, double check the ingredients and preparation. Recipes change. Don't assume anything is safe until you verify that it is.
   Be sure to visit FAACT's Dining Out section to learn more.

## Be sure to always keep the epinephrine in close proximity to the child!

Allergists recommend that all individuals at risk for anaphylaxis carry **two epinephrine products** with them at **all times** AND an **Allergy and Anaphylaxis Emergency Care Plan** signed by a board-certified allergist.

You should take your FDA-approved epinephrine products everywhere you go. Auto-injectors should be kept at room temperature (25°C, 77°F) until the marked expiration date, when they should be replaced. Your epinephrine auto-injector should not be refrigerated or exposed to extreme heat or light. Keep these temperature requirements in mind if you're thinking of putting your auto-injectors in your car's glove compartment, for example. The shelf life of neffy nasal spray is 30 months (meaning you won't need to replace it every year). It can be exposed to temperatures up to 122°F (50°C), making it potentially effective even if left in a hot car or outside, and can be thawed and used if accidentally frozen.

## **Increasing Advocacy & Awareness**

- Identify all places the child will visit and do a pre-visit to let those involved know about the child's food allergies- what they can/cannot have as a treat or snack, etc.
- Contact local 911/Fire Dept to inform them about the child's allergy ICE (In Case of Emergency).
- Discuss the child's food restrictions with others who may visit, to alleviate any tension and answer any questions.
- Ask guests to wash their hands when entering your home.
- Consider being an advocate for the child:
  - Follow FAACT's website and social media platforms.
  - Join a local support group.
  - Become involved with food allergy legislation.
  - Participate in a FAACT food allergy fundraiser.
  - Do your own food allergy fundraiser.
- Help teach the child skills to safely manage their food allergy and learn self-advocacy skills



# **Additional Ways to Get Involved**

### FAACT's Camp TAG (The Allergy Gang)

Camp TAG is a one-week day camp designed specifically for children between the ages of 4 – 13 and teen counselors, ages 14+. Camp TAG provides a safe place for children with food allergies, asthma, eosinophilic disorders, FPIES, Celiac disease, eczema, mast cell, and their non-allergic siblings to have fun – with no worries about allergic reactions. Camp TAG allows the campers to meet other children who share similar experiences, and it is a bonding and empowering week for the entire family.

Camp TAG is 95% fun and 5% educational, with age-appropriate

activities and games each day on food allergies, anaphylaxis, nutrition, the emotional impact of living with food allergies, and how to stay safe at school and at home. The curriculum was designed and reviewed by FAACT's Medical Advisory Board.

### **FAACT's Allergy Summit**

Knowing the importance of community engagement, support, and outreach firsthand to those managing food allergies, asthma, eosinophilic disorders (EGIDs), FPIES, Celiac disease, mast cell and systemic mastocytosis (SM), Alpha-Gal, and related conditions, this unique Summit unites EVERYONE and the companies who support food allergy living, management, and safety at ONE event!

### FAACT's Roundtable Podcast

Presented in a welcoming format with interviews and open discussions, FAACT's Roundtable podcast episodes cover all aspects of living with food allergies across the lifespan. You don't want to miss out, so subscribe, sit back, relax, and welcome FAACT into your homes!



# FAACT'S CAMP TAG





Allergy Summit

FAACT

Hyatt Lodge & Conference Center - Oak Brook, Illinois
The Voice of Food Allergy Awareness | FoodAllergyAwareness.org

### **Support Group Development**

Food allergy and anaphylaxis support groups have dramatically increased in recent years. Often times, food allergy support group settings are confidential and offered at little or no cost to members. Online food allergy support groups have also become popular, appealing to individuals and families with busy schedules and those seeking specific information in a timely manner. All of these benefits make support groups a valuable resource to communities across the world!



FAACT supports initiatives taking place across the nation and would like to recognize all those individuals who work tirelessly

to create a safe environment in their communities and schools for food-allergic individuals. Until there is a cure, we need to continue to educate, advocate, and raise awareness.



### **Education**

FAACT provides food allergy and anaphylaxis outreach, ongoing training and support to public and professional communities including grassroots organizations, schools, restaurants, hospitals, allergists, pediatricians, healthcare providers, CPR instructors, first responders, fire departments, paramedics, and other members of the community. Specifically, FAACT educates the general public about food allergies and anaphylaxis through summits, trainings, public outreach, community and professional partnerships, social media, our website and blogs, and other means.

FAACT website features an Education Resource Center for

patient and professional communities with free downloadable educational materials, including our school programs: FAACT for Schools and FAACT's Food Curricula Program for Schools.

### **Civil Rights Advocacy**

Through Civil Rights Advocacy, FAACT educates and informs food-allergic individuals, or their parents, of their rights to safely and equally participate alongside individuals without food allergies, particularly in schools. FAACT is intricately invloved in pursuing state and federal legislation in support of those with food allergies. FAACT maintains a very comprehensive, online **Accommodations Resource Center** and will continue to expand the information in the online Resource Center. FAACT offers one-on-one contact with our Civil Rights Advocacy attorney and staff to discuss issues, concerns, and questions involving civil rights and schools. FAACT has developed a system to track these contact requests while maintaining the privacy of the food allergy family (with the family's consent).



**FAACT's** Behavioral Health Resource Program provides numerous **FREE** resources focused on the psychological and social aspects of managing food allergies. Geared towards individuals, caregivers, and families, these resources may also be used as patient education materials for healthcare providers.



Food allergies require considerable time to manage and constant vigilance, which can pose a burden for both the food-allergic individual and caregiver. Learn more about the psychological, social, and quality of life impacts food allergies present in the **Psychological Impacts section**.



Presented in a welcoming format with interviews and open discussions, **FAACT's Roundtable podcast** episodes cover all aspects of living with food allergies across the lifespan.



Navigating life while managing food allergies can feel overwhelming at times. **The Behavioral Health Resource Center** offers informational guides and handouts on a variety of topics such as food allergy anxiety, self-care, food allergy parenting at various stages, and more!



**Self-care** is any activity that we do deliberately in order to take care of our mental, emotional, and physical health. Good self-care is key to improved mood and reduced anxiety. It's also key to a good relationship with oneself and others.



## **REFERENCES & RESOURCES**

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9. Food Allergy Management and Anaphylaxis Preparedness in a Suburban School District Varies by School Level

#### Bullying

#### https://www.FoodAllergyAwareness.org/education/bullying/

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2. Sicherer, Scott et al. "Bullying among pediatric patients with food allergy." Annals of Allergy, Asthma & Immunology, Vol 105, Issue 4 (October 2010).

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http://www.fda.gov/Food/GuidanceRegulation/GuidanceDocumentsRegulatoryInformation/Allergens/ucm059116.htm

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FDA recently issued a final rule allowing the use of the term "gluten-free" on food labels where the food product contains less than 20 parts-per-million (ppm) of gluten.

#### **Cross-Contact**

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