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

FoodAllergyAwareness.org



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 allergic 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

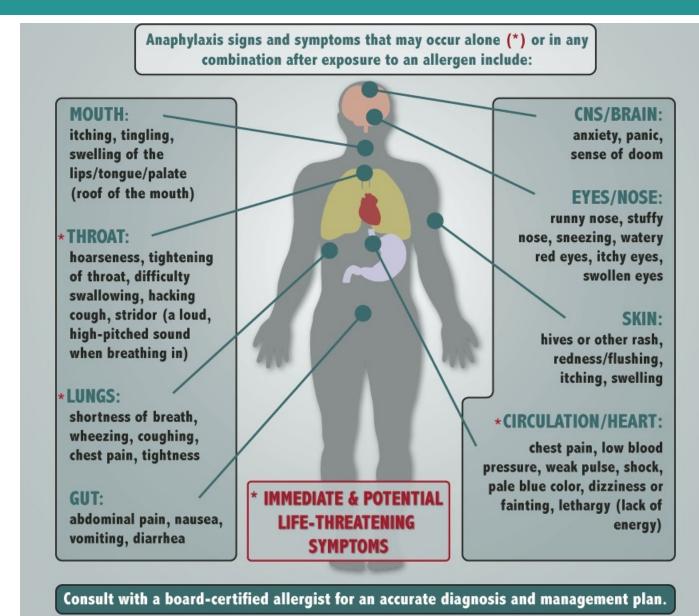
- Can be fatal if not treated promptly
- Can include a wide range of signs & symptoms
- Symptoms can occur alone or in combination
- Requires immediate treatment

(Follow child's allergy & anaphylaxis emergency plan)

- Injection of epinephrine
- 911
- Observation in ER 2-24 hrs recommended
- Anaphylaxis caused by a food can occur within **minutes** to several hours after food ingestion.
- 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!

Anaphylaxis Signs & Symptoms



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

Food Allergies & Asthma?

The lung, heart, and throat are immediate life-threating symptoms. It's important to note that a food allergic reaction can present symptoms the same as an asthma attack; however, asthma medication will **ONLY** treat an asthma attack, AND epinephrine will treat **BOTH**.

In the event of an emergency...

Refer to the child's allergy & anaphylaxis emergency plan

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 injected, 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 blocks 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 contridictions to giving epinephrine.
- Make sure you are trained on epinephrine **administration**.
- Administer epinephrine = **call 911.**

See next page for your Epinephrine Auto-Injector Options.

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

Auvi-Q by Kaléo

Website: www.auvi-q.com/ Available in Walgreen's: www.auvi-q.com/walgreens/ Dosage: 0.1mg/0.15mg/0.3mg Hold time: 2 seconds Needle: Retracts after injection Trainer: Included Savings Program: www.auvi-q.com/getting-auvi-q/ Administration Training Video: www.auvi-q.com/videos/



The Authorized Generic to Epi-Pen and Epi-Pen Jr Website: www.epipen.com/en/about-epipen-and-generic/ what-is-an-authorized-generic Dosage: 0.15mg/0.3mg Hold time: 3 seconds

Needle: Covered after injection Trainer: Included Savings Program: www.activatethecard.com/mygenericeai/? ga=1.45028076.935859954.1485174656 Administration Training Video: www.epipen.com/en/ about-epipen-and-generic/how-to-use-epipen

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Symjepi by Adamis Pharmaceuticals Corp. Website: www.symjepi.com/ Dosage: 0.15mg/0.3mg Hold time: 2 seconds Needle: Slide safety cover over needle Trainer: Yes, order at: www.symjepi.com/order_a_symjepi_training_device Savings Program: www.symjepi.com/symjepi_savings_program

Administration Training Video: <u>www.symjepi.com/</u> how_to_use_symjepi_



Epi-Pen and Epi-Pen Jr by Mylan

Website: www.epipen.com/en/ Dosage: 0.15mg/0.3mg Hold time: 3 seconds Needle: Covered after injection Trainer: Included

Savings Program: www.epipen.com/paying-for-epipen-and-generic#PatientAssistanceProgram Administration Training Video: www.epipen.com/en/

about-epipen-and-generic/how-to-use-epipen



The Authorized Generic for Adrenaclick by Impax Available in CVS Pharmacy: www.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.





Teva Epinephrine by Teva Website: www.tevaepinephrine.com/ Dosage: 0.15mg/0.3mg Hold time: 3 seconds Needle: Covered after injection Trainer: Included Savings Program: www.tevaepinephrine.com/savings Administration Training Video: www.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 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 to the kitchen to talk with 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: www.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 eight major food 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, and soybeans.
FALCPA requires that major allergens be declared, in plain English, on ingredient labels. Starting January 1, 2023, FALCPA will require 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 produced 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 product is allergen-free and there is no crosscontact.

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 you snack while watching TV, make it a 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

Hands

YES 📀

Soap and water

YES ✔ Hand wipes (*Wet Ones / Tidy Tykes)

NO 🔀 Plain water

NO 🔀 Hand Sanitizer

surfaces. Surfaces

YES 📀

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

NO 🔀 Liquid dish soap

Please note: Hand sanitizing gel is not sufficient to remove allergens.

Dining Out Tips

- Before dining out, check the restaurant's Web site 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 auto-injectable devices with them at all times AND an Allergy and Anaphylaxis Emergency Care Plan signed by a board-certified allergist.

Take the epinephrine auto-injectors everywhere you go, but they should be **kept at room temperature** (25°C, 77°F). The epinephrine auto-injector should not be **refrigerated** or exposed to **extreme heat or light**.

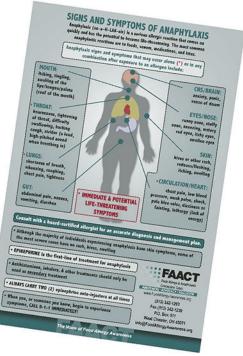
Increasing Advocacy & Awareness

- 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.

Share resources from FAACT.







Additional Ways to Get Involved

Camp TAG (The Allergy Gang)

Camp TAG provides a safe place for children with food allergies, eosinophilic disorders and asthma and their non-allergic siblings to have fun – with no worries about allergic reactions – and meet other children who share similar experiences. It is a bonding and empowering week for all campers, ages 5-13, including parents. Teens, ages 14+, may serve as volunteer teen counselors and receive community service hours for their time during the week.



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 (for children with food allergies and their families), and how to stay safe at school and at home. The curriculum was designed and reviewed by FAACT's Medical Advisory Board.



Teen Retreat

FAACT's Teen Retreat is all about teens and college students with food allergies, their non-allergic siblings – ages 11 through 23, and their parents. The weekend offers an informative program full of fun activities. Teens will learn about managing their food allergies and, more importantly, spend time with peers who have food allergies (and siblings who do not). Siblings are also affected when a family member has food allergies. Our Teen Retreat is a safe place for them to discuss their concerns with a group who not only understands but can share their own experiences, advice, and solutions.

Leadership Summit

FAACT Support Group Leadership Summit is a COMPLIMENTARY, two-day event dedicated to building collaborative communities that share a passion for raising awareness and preparedness of people with life-threatening allergies. The summits will present unique opportunities through workshops, lectures, networking, and activities for attendees to develop the leadership and organizational skills needed to improve their networks, as we as develop relationships with other leaders within their regions. Furthermore, attendees will receive routine updates throughout the year on best practices and success stories as a result of the summit.

FAACT's Leadership Summit



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. FAACT thanks you for your tireless efforts, amazing accomplishments, and positive contributions to communities across the nation!



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 Web site and blogs, and other means.

FAACT's Web site features an **Education Resource Center** for patient and professional communities with free and downloadable educational materials, including our school programs: FAACTs for Schools and FAACT's Food Allergy 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 involved in pursuing state and federal legislation in support of those with food allergies. FAACT maintains a very comprehensive, online **Civil Rights Advocacy 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 Resources Program

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.**



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!



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.



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.



FAACT's Diversity, Equity, and Inclusion Initiatives

DIVERSITY,



Did you know?

Black children are 7% more likely to have food allergies compared to white children.

FAACT formed its <u>Diversity, Equity, and Inclusion Advisory Board</u> with extraordinary food allergy and asthma community leaders, members, and advocates who bring rich, diverse backgrounds and conversations to the table. Our goal is to explore how FAACT can improve the diversity of our organization, our constituents, events, and initiatives; including discovering pathways for equity and inclusion while creating a safe and equitable space for our constituents to thrive, share, and learn about living with food allergies through education, advocacy, awareness, and research.

We are honored and humbled by the immediate response and formation of this important advisory board, and our commitment to the food allergy community grows deeper with the creation of this board.

In addition, each FAACT team member is actively participating in a private workgroup led by Living in Empathy, LLC to explore racism, equity, and inclusion. It is our belief that to support equity in health care, each team member must understand racism, equity, and inclusion, while embracing how to impact change. FAACT is also actively working with Living in Empathy, LLC on shared initiatives, along with the advisory board, in which Living in Empathy has joined. To establish long-term, sustainable change, FAACT is focused on the intervention of racist and biased structures and acknowledges that a bridge of trust and access needs to be built for impactful research to include BIPOC. We believe our goals will bring to light the importance of not only understanding diversity, equity, and inclusion, but the ability to intervene dysfunctional systems which create barriers to equitable healthcare.

For more information, please contact Eleanor.Garrow@FoodAllergyAwareness.org.



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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

https://www.FoodAllergyAwareness.org/food-allergy-and-anaphylaxis/cross-contact/

1. Perry, Tamara T. et al, "Distribution of Peanut Allergen in the Environment," Journal of Allergy and Clinical Immunology, May 2004, Vol. 113, No. 5.

Food Allergy Studies

1. Prevalence of challenge-proven IgE-mediated food allergy using population-based sampling and predetermined challenge criteria in infants. J Allergy Clin Immunolol 2011; 127: 668-676. <u>https://pubmed.ncbi.nlm.nih.gov/21377036/.</u>

2. Boyce JA, Assa'ad A, Burks AW, et al; NIAID-Sponsored Expert Panel. Guidelines for the diagnosis and management of food allergy in the United States: report of the NIAID-sponsored expert panel. J Allergy Clin Immunol. 2010;126(suppl 6);S1-S58. <u>https://pubmed.ncbi.nlm.nih.gov/21134576/.</u>

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