

Welcome to the Jaffe Food Allergy Institute at The Mount Sinai Medical Center.

We are pleased to offer specialized care focused on all types of food allergic disorders, covering all degrees of severity.

Since food allergies frequently go hand-in-hand with other allergies, we also provide expert care for the broad spectrum of allergic problems, including asthma, allergic rhinitis (hay fever), atopic dermatitis (eczema), drug allergy, hives, insect sting allergy, severe allergic reactions (anaphylaxis), immune system problems and many other allergic and immunologic disorders.

Whether you are coming to us for help with one issue or several, we are here to serve you and your family with the medical expertise, educational guidance, nutritional counseling and emotional support you may need. In addition, we will continue to assure that your family has the very best care in the years to come through our cutting-edge research, numerous ongoing studies and practical applications of the best that current science has to offer.

We have prepared this booklet as an introduction to successful living with food allergies. Our physicians, nurses, dietitian, and other Institute staff will provide you with detailed information for managing your or your child's food allergy. Additional resources are listed in the back and we are always available to answer any questions you may have about your or your child's treatment.

We are all looking forward to getting to know you and your family, and we are eager to work with you toward achieving a healthy, happy future.

Best regards,



HUGH A. SAMPSON, M.D.
Director, Jaffe Food Allergy Institute
The Mount Sinai Medical Center



welcome

The Jaffe Food Allergy Institute is proud to be one of the world's leaders in food allergy research.

During your visit, you will see materials about the various studies being conducted. If you missed seeing these, please call us! You or your child might qualify for a study. Our studies address improving diagnoses, treatment options, and quality of life for persons with food allergies. There are also many studies going on "behind the scenes" in our laboratories. Our studies have been funded by the government, not-for-profit organizations, private donors, and industry. All of our clinical studies are monitored very closely and are approved annually by Mount Sinai's Program for the Protection of Human Subjects. Patient safety always comes first.

Our clinical trials depend upon participants like you! Depending upon the study, participation may involve questionnaires and simple blood tests. For treatment trials, visits may include a number of tests.

Sometimes families are curious about participating in studies but not sure if the study is right for them. Simply put, clinical research is performed to find answers to important questions and without participants, we cannot get those answers! Safety, comfort and convenience for participants are our prime concerns. We work with you to ensure that you and your child understand all aspects of participation. Research participation is an altruistic commitment, and on behalf of our patients we very much appreciate efforts to find a cure and better management options.

Speak with your child's allergist to determine if there is a research study that may be appropriate for your child. Staff is available to discuss research studies with you. Look for our research newsletters and brochures! Stay informed!



Common Misconceptions About Research

Misconception: Treatment trials require a participant to have a severe allergic reaction.

Reality: This is not the case! Some trials include "feeding tests" where a tiny amount of the food is given periodically in slow, gradually increasing amounts to determine how much food would trigger a mild reaction. The studies are NOT trying to cause a severe reaction and feeding is stopped at the first sign of symptoms. The most common symptoms are rashes and mouth itching.

Misconception: If I participate, I might get a placebo and that would be disappointing.

Reality: In some trials there are placebos (an inactive substance, for comparison to the treatment being tested) and without them the trial would not be able to find a definitive answer. When undertaking a treatment trial, we are asking a question (Does this work?) and there is not yet an answer. Everyone in the trial is helping to find the answer. If the treatment works, it will then be available for everyone (even those who, for a short time, were on the placebo). Therefore, if the treatment helps, everyone benefits.

FREQUENTLY ASKED questions

What is a food allergy?

GOOD QUESTION! There is a difference between a food allergy and food poisoning or food intolerance, although the symptoms for all three may seem very similar.

An allergic reaction to food occurs when the immune system—the part of the body that usually fights infection—"attacks" harmless proteins in our food. This immune system response causes the body to release histamines and other chemicals, which can then cause symptoms ranging from vomiting and diarrhea to nasal symptoms, eczema, hives, swelling of the lips and tongue, coughing, wheezing, or asthma-like symptoms, and even a drop of blood pressure and loss of consciousness. A life-threatening allergic reaction is called anaphylaxis. A food allergy may be very mild or very severe, but it is always an immune system response.



A food allergy happens when the immune system, the part of the body that usually fights infection, "attacks" harmless proteins in our food.



The problems that many people experience after eating certain foods are often not caused by food allergy. For example, people may become ill from food poisoning. The culprit in that case is usually spoiled food. Or they may have food "intolerance." People with lactose intolerance, for example, cannot digest the milk sugar called lactose and may experience symptoms such as diarrhea and upset stomach. Food poisoning and food intolerance can make people feel very ill, but unlike severe food allergies, they are usually not life-threatening.



In children, the most common foods causing significant reactions are egg, milk, peanut, soy, wheat, tree nuts, fish and shellfish.

What foods cause allergies?

Although a person could be allergic to virtually any food, most people with food allergies are allergic to a relatively small number of foods. In children, the most common foods causing significant reactions are egg, milk, peanut, soy, wheat, tree nuts (for instance walnut, pecan, almond, cashew, pistachio, etc.), fish and shellfish. In adults, the most common foods are peanut, tree nuts, fish and shellfish. We are also seeing some increase in allergies to seeds like sesame, poppy and mustard, and more (usually mild) reactions to various fresh or raw fruits and vegetables.



What types of problems are caused by food allergies?

People are most familiar with sudden severe allergic reactions, such as anaphylaxis, caused by foods. However, sometimes chronic illnesses, such as skin rashes (atopic dermatitis or eczema) and certain digestive problems can also be caused by food allergies. Your allergist can help determine which symptoms are likely or unlikely to be due to foods.

What is atopic dermatitis?

Atopic dermatitis, or eczema, is a chronic skin disease estimated to occur in 15% of children. About one in three children with moderate to severe atopic dermatitis has a food allergy. In infants and young children, atopic dermatitis is often a "first sign" that the child is prone to allergy and may go on to develop food allergies, nasal/eye allergies to airborne allergens (like pollens and animal dander) and asthma. The skin of people with eczema is dry with an itchy, red rash. The urge to scratch is generally irresistible, and the scratching itself plays a major role in the development of eczema flares. Bacterial skin infections are common and in turn cause yet more itching and redness and inflammation. The skin also has an increased susceptibility to certain viral infections. Although eczema may make your child uncomfortable (we have many therapies that will help!), it is not generally dangerous provided appropriate treatment is given to clear up the skin lesions. None of the available treatments cures eczema permanently. Even if all food allergies are properly diagnosed and appropriate foods are avoided, eczema will come and go. Additionally, there are many *non-food* triggers that commonly cause eczema flares, including stress, fever or viral illness, sweating, weather changes, and irritating clothing. The good news is that eczema generally improves with age.

How is food allergy diagnosed?

Your Institute doctor will obtain a medical history and perform a physical examination to determine whether a problem is related to foods or other allergic triggers and will decide if further testing is needed. Typical tests include allergy skin prick tests and/or blood tests measuring IgE antibodies to specific allergens. Your doctor may also suggest an "oral food challenge," a test where the food is eaten gradually under medical supervision to determine if it is tolerated or not.

How is food allergy treated?

Once a diagnosis is made, education is provided, which includes instructions on avoidance of the problematic foods and how to recognize and treat a food allergic reaction. Researchers at the Institute are involved in studies to develop better treatments and possible cures for food allergies.

Will food allergy go away?

Food allergy to egg, milk, wheat, and soy often resolves in childhood. Peanut, tree nut, fish and shellfish allergies usually persist. However, it may be possible to outgrow any allergy with time. About 20% of young children may eventually outgrow peanut allergy and about 10% outgrow tree nut allergies.

Can I prevent food allergies?

You did not cause your child's food allergy. We see children with peanut allergy who, as far as anyone knows, never were exposed to any peanut but still showed up with a strong positive blood test. That being said, there may be some measures you can take to lessen the chances of your children developing eczema (atopic dermatitis) or possibly food allergies. Most experts suggest that breast feeding is a helpful means to delay or prevent atopic dermatitis. It's also advised to delay the introduction of solid foods until 4 to 6 months of age. Discuss these and other recommendations with your pediatrician and allergist. However, understand that none of these suggestions is set in stone. As much progress as we have made in the past few years, there is still a limited amount

of medical literature available on this topic, and even experts may disagree on some issues. What's more, every family situation is different. We can help you weigh the alternatives and come up with a plan that works for your family.

How worried should I be?

As a chronic condition, food allergy affects each individual and family differently. Any time you are faced with the potential for anaphylaxis, it is to be taken seriously. With that being understood, anaphylaxis is preventable and treatable, and when your child comes to the Jaffe Food Allergy Institute, you will be provided the education and tools necessary to make informed decisions and manage your child's food allergies. Your life and activities should be as normal as possible. For example, it should not be necessary to exclude social events, travel, or school. Every family and individual has their own methods to cope with chronic illness.



anaphylaxis

SYMPTOMS AND TREATMENTS

What is “anaphylaxis”?

Anaphylaxis is a severe, potentially life-threatening allergic reaction. Technically, anaphylaxis occurs when an allergic reaction comes on suddenly and affects several parts of the body, sometimes in a severe and progressive way. Anaphylaxis is a true emergency, requiring prompt medical treatment.



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What are the symptoms of anaphylaxis?

Symptoms almost always start within minutes after an exposure, although a delay of up to an hour or more is possible. Symptoms can affect the skin (swelling, hives/welts, itchiness, redness), gut (itchy mouth, stomachache, nausea, vomiting, diarrhea), throat and lungs (hoarseness, difficulty swallowing, throat closing, trouble breathing, wheezing, repetitive coughing) and circulation (paleness, dizziness, passing out, low blood pressure, loss of pulse). A “feeling of impending doom” is often described. Women may experience uterine contractions. Mild symptoms limited to parts of the body being affected are usually not thought of as life-threatening anaphylaxis (skin symptoms alone, itchy mouth alone, stomachaches alone). Sometimes a reaction will subside and then start up again 1 to 3 hours later. Here is a scheme for thinking about the symptoms:

Area of body	Severe	Mild
Breathing	<ul style="list-style-type: none"> throat tightness wheezing (asthma) shortness of breath repetitive coughing turning pale/blue 	<ul style="list-style-type: none"> nasal congestion rhinitis (runny nose) slight cough
Gastrointestinal	<ul style="list-style-type: none"> Obstructive tongue swelling 	<ul style="list-style-type: none"> nausea vomiting diarrhea stomach pain itchy mouth/ear canal lip swelling odd taste in mouth
Skin		<ul style="list-style-type: none"> flushing/red itching hives swelling eczema flare
Heart/circulation	<ul style="list-style-type: none"> hypotension (low blood pressure) shock syncope (faint) poor/weak pulse chest pain 	
Other	<ul style="list-style-type: none"> “impending doom” 	<ul style="list-style-type: none"> eyes red/itchy, uterine contractions

What medical problems might look like anaphylaxis?

Choking, panic attacks, fainting spells, seizures and heart attacks share some common symptoms with anaphylaxis. Sometimes it is truly hard to tell what is happening. If a person known to have food allergies has the typical symptoms after eating, anaphylaxis should be considered and the person should be treated with emergency medications. Make sure to consider the possibility that the person could be choking (in which case the Heimlich maneuver would be helpful) and to provide basic life support (CPR) if needed, while medical personnel are on their way.

Who is at risk for anaphylaxis?

There are no scientific studies to answer this question, and there are currently no specific tests available to provide us with this information. In fact, anyone with a food allergy can have a severe allergic reaction...even if there is no prior history of a reaction. We do know that a person who has already experienced severe allergic reactions is certainly at risk. There appears to be a greater chance for a severe reaction if the person has underlying asthma, but not all asthmatics with food allergy will have severe reactions. The foods known to be responsible for a disproportionately higher rate of anaphylaxis are peanut, tree nuts, seafood and milk. However, an allergic reaction to any food could potentially result in anaphylaxis. The literature suggests that when progressive symptoms are denied by the allergic person and allowed to progress without giving treatment, there are bad outcomes. This is not different from what is seen with many other medical emergencies (heart attacks). Unfortunately, with food allergy, this scenario seems to be more common among teenagers and young adults.



Epinephrine is the only medicine clearly indicated to stop a severe allergic reaction. An antihistamine, usually Benadryl® or Zyrtec®, is an important medicine as well. Your doctor will provide you with an individualized “action plan.”

How can I predict the severity of my food allergy?

Unfortunately, you can't. The skin test size or the blood test result (food specific IgE level) does NOT predict the severity of potential food allergic reactions. That is what makes food allergy a very upsetting chronic illness. Some things that might play a role in the severity include the amount of allergenic food eaten and underlying health (for example, the presence of asthma). The notion that each reaction gets progressively worse is a myth. Because these variables are quite complex, each person with food allergy should discuss the details with his/her allergist to get a better feeling for the risks, symptoms, and treatments.

What can I do to prevent anaphylaxis?

Make sure you and your allergist start by confirming the particular food allergy/allergies so you know what you need to avoid. The general aims are (1) avoidance of the causal food and (2) preparedness at all times to promptly treat a reaction if one should occur. We recognize that allergen avoidance and knowing how to treat an allergic reaction requires a lot of effort and education and may require you to teach others about managing food allergies. Don't forget that a reaction can occur anywhere, and always plan accordingly (by having medications, emergency care plans, a MedicAlert bracelet, etc., at all times).

What can I do to treat anaphylaxis?

Epinephrine is the only medicine clearly indicated to treat anaphylaxis. While antihistamines can be used to treat some symptoms such as hives, and asthma inhalers may treat some breathing symptoms, **neither will reverse the symptoms of anaphylaxis.** Your doctor will provide you with an individualized “action plan.” If you have been given epinephrine and the reaction stopped, you still must get emergency attention (call 911, etc.) since the reaction could recur within minutes or hours. **Stay in the ER for at least 4 hours following a strong reaction just to be sure it is really over.** If you call 911, be sure to tell them exactly what has happened, for example: “My child with food allergy ate fish, is having trouble breathing, and I gave a dose of epinephrine.” This helps the dispatcher to send the right type of ambulance. The most common side effect of epinephrine is a fast heart rate (“racing heart”). This is generally a very safe medication for children and young adults. Epinephrine was the drug given for simple asthma attacks before inhaled medicines were available. Make sure you know how to use your epinephrine injector, review monthly, and check the expiration date. Most people carrying this medicine do not know how to use it! Don't be one of them! Teach others using available trainers.

SPECIAL programs & resources AT THE INSTITUTE

The Jaffe Food Allergy Institute offers comprehensive treatment of food allergies and their related allergic disorders including asthma, atopic dermatitis (eczema), allergic digestive disorders, hay fever, medication allergies and many other allergic problems. We understand that food allergy treatments are limited, that living with food allergies can be stressful, and that restricted diets may lead to nutritional problems. The programs and resources featured on the following pages contribute to our holistic approach to treatment.





Special programs and resources provide a holistic approach to food allergies

The Center For Integrative Medicine

The Center for Integrative Medicine at the Jaffe Food Allergy Institute focuses on traditional Chinese medicine treatments for children and adults. This center seeks to provide additional health care options for patients with multiple allergic conditions who may be interested in complementary and alternative medicine therapies to be used in conjunction with an established management plan from their traditional physicians. Traditional Chinese medicine, used in China and other Asian countries for centuries, is now part of mainstream medicine and is beginning to play a larger role in the American health care system. The Center will facilitate clinical research and education and offer treatment options such as herbal remedies, acupuncture, and acupressure for allergic conditions such as eczema associated with food and environmental allergies.

The EMPOWER Program

The EMPOWER (*Enhancing, Managing, and Promoting Well-being and Resiliency*) Program at the Jaffe Institute is staffed by professionals with particular expertise in managing behavioral and emotional issues in children with food allergy and their families. The program offers individual consultation, referral services and group treatment to patients and their families. As with other Jaffe Institute centers, an important mission of the EMPOWER program is to engage in research efforts. We aim to better understand the extent, reasons for, and management of distress in food-allergic individuals and their families, and we aim to help patients and families improve coping abilities and develop enhanced resilience. The program's focus on enhancing resiliency is unique, and we hope that it will serve as a model for providing multidisciplinary, holistic care within the Jaffe Food Allergy Institute and beyond. If you have

questions or concerns about the emotional aspects of living with food allergy or with managing your child's allergies, please discuss this with your doctor or ask about our EMPOWER program. Also, whether or not you have questions or worries, please consider participating in the EMPOWER program's research and screening efforts. You can help us improve our understanding of our patients' and families' concerns and strengths. Together, we may discover ways to enhance coping with food allergies.

The Center for Eosinophilic Disorders

Eosinophilic esophagitis (EoE) is a disease of the esophagus (the tube that connects the mouth to the stomach) caused by food allergies. Certain foods trigger EoE by causing allergy cells and other white blood cells, called eosinophils, to migrate to the esophagus. Symptoms may include stomach pain, vomiting, heartburn, difficulty swallowing, poor appetite, food refusal, and poor growth. These symptoms can mimic acid-induced reflux; however, they usually do not improve with antacid therapies that are often used to treat reflux. Treatment for EoE includes dietary modifications and other medical therapies. Special expertise is needed in treating this condition, since food allergens that trigger EoE work in a very special way, different from what has been traditionally known. If you have or your child has symptoms suggestive of EoE, please discuss them with your doctor, who may refer you to our Mount Sinai Center for Eosinophilic Disorders at the Jaffe Food Allergy Institute. At the Mount Sinai Center for Eosinophilic Disorders, you will encounter a caring team of professionals who have specialized knowledge and expertise in diagnosing and treating EoE and other eosinophilic gastrointestinal disorders. The team is multidisciplinary, consisting of a gastroenterologist, allergists, a dietitian and a psychiatrist. The Mount Sinai Center for Eosinophilic Disorders is also involved in research aimed at developing optimal treatments for children and adults living with EoE.

Nutritional Management

Every child needs adequate nutrition to grow and develop properly. Each food or food group provides a unique set of nutrients necessary for growth; therefore, any dietary restriction will present a challenge to adequate nutrition. Multiple food allergies make providing a nutritionally complete diet even more challenging and may put your child at greater nutritional risk. Our registered dietitian can help determine your child's specific nutritional needs and create a plan to meet those needs within the confines of the allergen-restricted diet. Our goal is to provide a plan for safe and healthy eating that is still fun, tasty, and appealing so that children can look forward to, rather than dread, coming to the table.



ALWAYS read the label!

But beware of “hidden allergens” as well!

In the food allergy universe, learning how to read the ingredient labels printed on packaged foods, and committing to reading them each and every time you open a fresh package (because ingredients can and do change), are two of the most important things you can do to stay safe. Fortunately, labeling laws are making it easier to identify products that have common allergens in them. Your doctor will provide you with additional information about reading labels. Pay attention as well to the words printed below the ingredients list. Frequently there will be an advisory warning, such as “this product has been manufactured on lines processing wheat, milk and nut products.”

In addition to reading labels, you must also be able to identify where hidden allergens may be lurking. Here are just a few examples: If you have a milk allergy, think twice before ordering sliced cold cuts from the deli. The blade slicing your turkey may have sliced

cheese for the previous customer. If you have a peanut or nut allergy, think about that scoop at the ice cream shop. Did it just scoop some butter pecan before dipping into your chocolate chip? At the bakery, did the bowl that held the batter for your corn muffin previously hold the batter for the banana-nut bread? At restaurants, be sure to inform your server of your allergy. Allergens may be part of coatings, may be transmitted through deep frying, may be used as thickening agents, or just be included for novelty’s sake in dishes where you would never expect to find them. Dealing with food allergies means looking at the world in a new light, and at times it may seem daunting. The Jaffe Food Allergy Institute is here to help you every step of the way. Never hesitate to contact us with questions, concerns or for additional advice. Our team of experts is here to serve you and your family in every way we can.

Resources Contact These Groups for More Information

The Elliot and Roslyn Jaffe Food Allergy Institute at the Mount Sinai School of Medicine

Box 1198
One Gustave L. Levy Place
New York, NY 10029
212-241-5548
<http://www.mssm.edu/research/programs/jaffe-food-allergy-institute/about-us>

Food Allergy Initiative (FAI)
515 Madison Avenue, Suite 1912
New York, NY 10022-5403
Tel.: 212-207-1974
info@faiusa.org
www.faiusa.org

The Food Allergy & Anaphylaxis Network

11781 Lee Jackson Highway, Suite 160
Fairfax, VA 22033-3309
800-929-4040
www.foodallergy.org

American Academy of Allergy, Asthma and Immunology

611 East Wells Street
Milwaukee, WI 53202
414-272-6071
800-822-2762
www.aaaai.org

Consortium of Food Allergy Research (CoFAR)

Food Allergy Education Program
<https://web.emmes.com/study/cofar/EducationProgram.htm>

MedicAlert Foundation

2323 Colorado Avenue
Turlock, CA 95382
888-633-4298
www.medicalert.org

American Partnership for Eosinophilic Disorders (APFED)

PO Box 29545
Atlanta, GA 30359
Phone: 713-493-7749
www.apfed.org

Asthma and Allergy Foundation of America

1233 20th Street, NW, Suite 402
Washington, DC 20036
800-7-ASTHMA
www.aafa.org