



**Texas Children's  
Hospital®**

Winter 2016-17

News Alert



The 2<sup>nd</sup> annual Cooking Up a Cure, an event that supports the rapidly growing Food Allergy Program at Texas Children's hospital took place on the evening of January 19. The program provides cutting edge research, education and patient care to children suffering from food allergies, and has quickly become a model program for other hospitals and programs around the country and internationally. The memorable evening held at the industrial chic Astorian loft featured food prepared by Houston's top chefs.

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# Food Allergy Program Newsletter



## Texas Children's Hospital's 3<sup>rd</sup> Food Allergy Program Symposium

The Third Annual Food Allergy Symposium, held on September 24, 2016, and was a tremendously successful event! It was sold out with 180 registrants and there were several walk-in participants.

Families of children with food allergies were educated about the basis of food allergies, how to manage their child's diet and nutrition, anxiety, legal issues, gastrointestinal problems in children with food allergies and what it is like to participate in research studies. Several experts spoke, including Dr. Katherine Anagnostou, Dr. Sara Anvari, Dr. Gretchen Browne (psychologist), Dr. Anthony Olive (gastroenterologist), Ms. Lucie Shipp Tredennick, JD and food allergy dietitians Ms. Madelyn Wilson, RD and Jillian Davis, RD.

Ms. Avina Nguyen led the Children's Session with separate sessions for both teens and young children. A teen patient advocate, Ms. Adriana Kelly, led the young children's session.

Ms. Theresa Aldape led a tremendous Food Allergy Family Network meeting with input from the community leaders and a special presentation by a father, Mr. Mike Oldham. The very first Eosinophilic Esophagitis Support Group meeting was held by Ms. Damaris Cortes and Dr. Olive. Ms. Rosana Morales was instrumental in coordinating the event.

A special thank you goes out to our very own TCH IAR participants, who included Ms. Daisy Tran, Ms. Kathy Pitts, Ms. Lorraine Lyter-Reed, Dr. Karen Tuano, Dr. Maya Gharfeh, Dr. Dipika Patel, Dr. Mayra Hernandez, Dr. Sara Nandiwada, Mrs. Chivon McMullen Jackson, Ms. America Lueso, Ms. Patricia Perez, and Mrs. Kim Nguyen. TCH Volunteer Services also helped under the leadership of Ms. Avina Nguyen and Ms. Theresa Aldape.

This would not have been possible without the outstanding coordination and administrative leadership of Christina Cowperthwait.

# Food Allergy Symposium: One Speaker's Experience



## About Dr. Maya Gharfeh, allergy and immunology specialist

I am a second year pediatric allergy and immunology fellow at Texas Children's Hospital/Baylor College of Medicine. My areas of interest include food allergy, allergic rhinitis and sinusitis, asthma, eczema and eosinophilic disease. I completed my pediatric training and chief residency at Nationwide Children's Hospital in Columbus, Ohio. My free time is predominantly spent creating memories with my loving husband, our adorable one year old daughter and our cavapoo pup. You can follow me and read more about my insights on being an allergist mom on

<http://www.allergistmama.wordpress.com/>



## Contributed by Dr. Maya Gharfeh, Allergy & Immunology specialist

I had the opportunity to participate in the third annual Texas Children's Hospital Food Allergy Symposium. All I can say is, wow; what a truly incredible time it was for me! This event was created for our pediatric food allergic community with a goal of educating our families and providing exciting updates in the world of food allergies. In addition to the general audience sessions, a youth track, divided by age groups, was provided to specifically address the interests and questions of the young patients.

The teens first spent time getting to know one another through a few icebreakers. It was fun to see the teens move around the room and begin to interact with one another. After the ice breakers, Dr. Gretchen Brown, a clinical psychologist who currently sees food allergic patients in her practice, spoke on a subject very real to these teens – bullying. After affirming the teens' emotions and experiences, she provided the group with practical resources for dealing with bullies at school, as well as some very practical relaxation techniques through an iPhone app to use in stressful situations. The teens loved it and even started downloading the app on their phones!

I then had the opportunity to speak to the teens about my experience, not only as a physician taking care of food allergic patients, but also a mother. You see, my young daughter was recently diagnosed with an allergy to pistachios. I shared with the teens my

daughter's story and how so many of my thoughts after her diagnosis were similar to their own. I talked about the evolution of emotions anyone who is newly diagnosed with a food allergy goes through and how these emotions have helped me as a physician relate to my patients even more than I could have ever imagined. They were very interested and even asked some very insightful questions about my daughter's symptoms that prompted the diagnosis. They understood what it meant to have a food allergy and they owned it! But what I was completely unprepared for was how much they all impacted me. I finally shared with the group that as I looked at their young faces, I saw my "grown-up" daughter. All I could see was my little girl, growing up to be like one of these amazing kids. As I shared with the teens that morning, the greatest message I wanted them to take away after the symposium was that we at Texas Children's are so proud of them for being strong in their diagnosis and confident as they engage with their friends and families all around them. Their strength is an inspiration to not only their parents, but also their entire community.

So, thank you, Texas Children's, for sponsoring such a great event and thank you to our patients and their families who truly are the reason we at Texas Children's do what we do.



**Madelyn Wilson is a Registered Dietician with Texas Children's Hospital and works with the Allergy and Immunology Service. She led the breakout session on "Dietary Tips for Food Allergy Families".**

**Contributed by Madelyn Wilson, RD,**

**What is important on a food label**

If your child is allergic to any of the Top 8 allergens: Cow's milk, egg, soy, wheat, tree nuts, peanut, fish or shell fish; the label will say in **BOLD** if the product contains any of these items. If your child's allergen is not in the Top 8, it is important to read the entire ingredients list to catch any hidden allergens.

Remember to ALWAYS read the label EVERY TIME you buy a product. Even if it is the same brand, the company can change their recipe without alerting the public.

**Is my child missing any nutrient by eliminating his/her allergen from their diet?**

If your child is eliminating all cow's milk, it is important to supplement with a calcium and vitamin D supplement.

If your child has more than one food allergen, it may be a good idea for them to take a multivitamin. Please note, that some vitamins do have food allergens in them. Make sure you find one that is safe!

**What do we do when dining out?**

Ask around, other families with food allergic children may have suggestions on where to go. The website, Safefare.org is developing a database of restaurants based on zip codes that are safe for people with food allergies.

Pick a restaurant that best fits your needs. It is best to avoid riskier choices, which could include:

- Buffets: With a wide variety of foods so close to one another, the risk for accidental exposure and cross-contamination is high.
- Bakeries: There is a high risk of cross-contamination. Many items are made with the some of the top 8 allergens and many are typically not packaged.
- Restaurants that serve pre-made foods: The staff may not have an accurate list of the ingredients in a pre-made item. Since the dishes are not prepared from scratch, you can't ask the chef to remove the problem ingredient from an item that would otherwise be safe to eat.
- Restaurants are known to use allergens in many dishes. For instance, peanuts and other nuts are used frequently in Asian cuisines. In ice cream parlors, shared scoops increase the risk of cross-contamination. If you have a fish or shellfish allergy, it's a good idea to avoid seafood restaurants.

Consider chain restaurants, especially when you're traveling. Each restaurant is likely to use the same ingredients and prepare foods the same way, and a growing number are allergy-aware. If you plan to attend a catered event where the food will be prepared in advance, ask if it's possible to provide an allergy-friendly option.

**Meal Selection**

Keep it simple. If you have to ask a lot of complicated questions about the items on a menu, ordering more simple fare—like a baked potato, broiled chicken or steamed vegetables—may be the safest way

# Standout Q/A's from Allergy Symposium: Dietary Tips for Food Allergy Break-Out Session



**Symposium Attendees reading food labels.**

# Standout Q/A's from Allergy Symposium: Legal Issues Break-Out Session



**Lucie Shipp Tredennick  
receiving a hug from Dr. Davis.**



Contributed by Lucie  
Shipp Tredennick, J.D.

**This general information is provided for educational purposes only and does not constitute legal advice. The specifics of each situation are different, and if you need advice about your specific situation, you should consult your own attorney.**

## **What is generally required by law of private schools for food allergic children?**

Requirements for private schools vary by funding source and whether or not the school is run by a religious institution. Where the school does not accept federal funds, as most private schools do not, accommodations will be at the discretion of the school's administration in a manner consistent with legal requirements, based on the administration's judgment, policies, and written documents, like handbooks. It is imperative that you approach your school's administration in a collaborative and open manner, remembering that everyone has a vested interest in making a workable plan that keeps your child safe. Provide your school leaders with documentation and work together to train personnel and brainstorm solutions about medication storage and other issues. Private schools that accept federal funds are required to follow certain federal laws related to accommodation and the prevention of discrimination, and an attitude of openness and collaboration can be key here, too. Most students with food allergies qualify under the ADA and Section 504 as having a qualifying disability, so if those laws apply to your school, you can ask to meet to prepare a 504 Plan, based on your child's medical documentation and the judgment of the 504 team. The 504 Plan allows you to create, in collaboration with the school, a written management plan outlining how the school will address the individual needs of your child and allow your child to participate safely and equally alongside his/her

peers during all normal facets of the school day. These written plans come in a variety of shapes and sizes, ranging from a one-page handwritten form to a 20-page plan made up of multiple components (IHP, Food Allergy & Anaphylaxis Emergency Care Plan, Cafeteria Procedures, a Transportation Plan, & a Staff Education Plan).

## **What about for young children in day care? Does the Americans with Disabilities Act or "ADA" apply?**

Often, yes. Privately-run child care centers, like other public accommodations, such as (non-religious) private schools, recreation centers, restaurants, hotels, movie theaters, and banks, are subject to title III of the ADA. Child care services provided by government agencies, such as Head Start, summer programs, and extended school day programs, must comply with Title II of the ADA. Child care centers that are actually run by religious entities such as churches, mosques, or synagogues are not governed by the ADA, as they are activities controlled by religious organizations. These laws apply to a child care center's interactions with the children, parents, guardians, and potential customers that it serves. In broad terms, this means that covered centers cannot discriminate on the basis of disability, and would be required to make some modifications to their program to ensure a disabled child's participation, as long as the modifications/accommodations are reasonable and do not fundamentally alter the nature of the program. In any situation, when a parent is attempting to work with his or her child's school or day care in obtaining accommodations, a generally effective method is to provide clear documentation - along with requests for modifications and accommodations that are clear and reasonable - using a collaborative approach.

A child care center's employment practices are covered by other parts of the ADA and other laws aimed at preventing discrimination and are not addressed here, but can be found online on the Equal Employment Opportunity Commission's website.



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The Health Museum  
JOHN P MCGOVERN MUSEUM OF HEALTH & MEDICAL SCIENCE  
A real body of knowledge



Contributed by  
Christina Nance, Ph.D.

**Texas Children's Hospital-Food Allergy Program Collaboration with The Health Museum**

It began with a glimmer of an idea to spread food allergy information to the Houston community. The clinical team, led by the director, Dr. Carla Davis, with a vision by clinical team members, Kathy Pitts, Daisy Tran, Theresa Aldape and Lorraine Lyter-Reed, of the Food Allergy (FA) Program at Texas Children's Hospital (TCH) stepped out of the box and reached out to The Health Museum (THM) of Houston. THM directors, Meg Naumann, Hao Nguyen and LaTanya Miles facilitated the collaboration with TCH-FA with the mission to educate the Houston community about food allergy.

The initial collaboration, executed by Dr. Christina Nance (TCH-FA), launched in August, 2016, began with a venture into the "digital" world. The TCH-FA clinical team led by Avina Nguyen with Daisy Tran, Madelyn Wilson and Christina Cowperthwait at TCH-FA Program created digital-based information to link to THM digital world of Twitter, Facebook, Snapchat, web links and blogs.

The mission of the TCH-FA-THM, now a consortium, grew with the ambition to "move" outside the walls of THM. The award of funding from HEB has now allowed the consortium to grow with the capacity to reach even further into the Houston community in spreading the food allergy information. Now the TCH-FA-THM-HEB consortium is developing and exhibiting in mid-2017 a "mobile food allergy-based" exhibit. This mobile exhibit will travel to HEB stores, as well as, THM and TCH-based events. The TCH-FA clinical team, in concert with THM, is developing videos and hands-on educational information on food allergy to disseminate through the Houston community throughout 2017. What began as a glimmer has flared into fireworks with future goals and potential donations to expand the dissemination of food allergy information throughout the Houston community.

# Food Allergy Program Collaboration Announcement

## What is a food allergy?

A **food allergy** is an abnormal response of the immune system where your body recognizes a food as an invader and wants to get rid of it!

### Did you know?

YOUR immune system protects your body against germs and other invaders!



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**The digital team contributed infographics to the The Health Museum's Facebook page.**

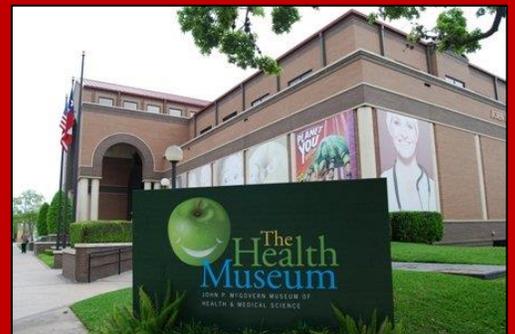
## Did you know?

Cow's milk, egg and soy allergies typically present in childhood and most kids outgrow them.



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# Food Allergy Family Network (FAFN) Update

Report by Theresa Aldape, LMSW

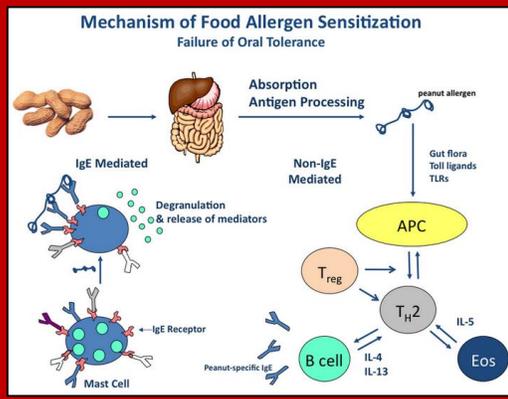
The Food Allergy Family Network (FAFN) at Texas Children's Hospital (TCH) began in 2015. In January 2016, six leaders were trained at TCH to provide family-centered support to families living within their communities. Our second year was an outstanding year. We provided education, support and resources for families living with food allergies in and around the Houston area. To expand our efforts in 2017, we recruited 7 additional network leaders giving us a total of 13 FAFN leaders who are actively engaged in the community. The leaders are all very energetic, informative, supportive and especially helpful to anyone who reaches out to them for support. They have volunteered at the Food Allergy Symposium, Food Allergy Awareness Day and the FARE Walk. The FAFN also joined the food allergy team members at various schools and health fairs in 2016. Daisy Tran, RN, Dr. Davis and our FAFN leaders have presented at 3 schools already in 2017.

We achieved various milestones in 2016, we 1) made contact with 842 people in the community, 2) purchased materials with our name, logo, and contact information to spread awareness 3) represented TCH FAFN at the FARE Walk with the leadership of Ms. Daisy Tran, RN, 4) led informative and supportive meetings throughout the year and at the Food Allergy Symposium and 5) Daisy Tran, RN and Theresa Aldape, LMSW were invited to join FARE's Community Engagement Council (CEC) in order better assist raising awareness in the community and being an advocate for those with food allergies. Rahma Sarwar, a FAFN leader, has also volunteered to join the CEC.

The FAFN leaders are listed below. Please reach out to them for support, information and also share ideas to keep our children and adolescents with food allergy safe in the community. I would like to say thank you to every family who has attended the various activities at Texas Children's Hospital. The Food Allergy Team have learned so much from each of you including the children and adolescent group. We are always gathering ideas and sharing it with others! For this, we are eternally grateful. Please feel free to reach out to the leader near your home or contact me directly at [tmaldape@texaschildrens.org](mailto:tmaldape@texaschildrens.org) or 832-824-1385.

## Food Allergy Family Network Leaders

Name	E-mail	Houston Area	Phone Number
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Daisy Tran, RN	<a href="mailto:dxtran1@texaschildrens.org">dxtran1@texaschildrens.org</a>	Lead Research Coordinator	(832) 824-3398



# Food Allergy Program Ongoing Clinical Study Update

Contributed by Daisy Tran, RN

## Open for Recruitment:

### Polyfunctional Flow Cytometry Study

The purpose of this study is to better understand how the immune system functions to protect its host and to develop better methods to identify and treat food allergies. This study consists of a blood draw.

### Microbiome Influences on the Development of Food Allergic Diseases in Children

Commensal or "good" bacteria and fungus species live on everyone's skin, mouth and intestines and take part in the body's biological functions. Evidence from recent research suggests that these microorganisms may play a part in food allergy. This study will evaluate the numbers and types of "good" and "bad" species in the gut of study participants. Eligible participants include infants to children up to 18 years old with food allergies who have a sibling without food allergy. This study consists of a single stool sample, skin swab, and mouth swab for the child and the sibling.

## Future Study:

RAMSES Peanut Capsule Study: Enrollment in the trial will hopefully begin in Summer 2017. Details to announced in the near future!

## Closed for Recruitment:

### Phase 1 Peanut Oral Immunotherapy Trial

Participants in this trial ingest a daily dose of peanut flour for 3 years. By the end of the first year, the child will be ingesting approximately 20 peanuts per day. Participants will have blood work obtained at various time points during the study. All patients will undergo an oral peanut challenge at the end of the study to determine their level of peanut tolerance.

### Phase 3 PALISADE Peanut Capsule

This is a 1 year study that desensitizes children to 300mg of peanut protein. A food challenge is performed at entry and then qualifying participants come in every 2 weeks until their maintenance dose is reached. This study requires the child to ingest a daily dose of peanut capsule. A food challenge is performed at the end of the study.

### PHASE 3 PEPITES Peanut Patch

This study lasts 1 year and requires a daily application of a patch to the back. The aim of the study is to assess the efficacy and safety of the Viaskin® Peanut patch dosed at 250 µg in peanut-allergic children from 4 through 11 years of age.

### Phase 3 REALISE Peanut Patch Trial:

This is a 3 year study looking at the safety and therapeutic benefit of the Viaskin® Peanut Patch dose at 250 µg. Children aged 4-11 years apply a daily patch to their back. No food challenge is required on this trial.

### Cow's Milk Allergy PRESTO Study

This study aims to compare an improved version of a special cow's milk-free baby formula with and without probiotics to see if it can modulate a baby's immune system as well as prevent the development of other food allergies.

### Eosinophilic Esophagitis (EoE) Studies

The 4 food elimination diet study is aimed at eliminating the four most common food triggers then reintroducing the foods slowly over time. The EoE Clinical Therapy Trial is aimed at comparing swallowed steroids to test based elimination diet in the management of EoE.