

ASTHMA & ALLERGY

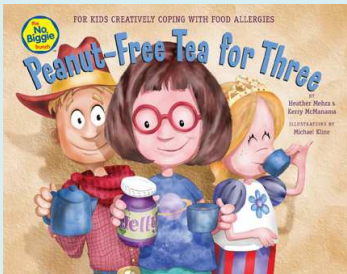
BULLETIN

ASTHMA AND ALLERGY FOUNDATION OF AMERICA • NEW ENGLAND CHAPTER

Food Allergy Story Hour

with the creator of the
"No Biggie Bunch,"
a group of diverse and
adventurous young characters
who have food allergies but
are not defined by them. They
are smart, prepared and safe
while maintaining a great
attitude and having fun.
(www.nobiggiebunch.com)

Heather Mehra will read and
talk about her books:



Saturday, Nov. 5, 2016
10:30 a.m. - 11:30 a.m.
Newton Public Library
330 Homer St., Newton, MA

- For children up to age 8
- Autographed copies will be available for purchase.

FREE!

No need to register.

RESEARCH UPDATE

Leaving Home: Support Needed for Older Teens with Allergies

By Frank J. Twarog, MD, PhD

As our children move into late adolescence and either become independent at their work or leave for college they need to deal with a multitude of issues, among which is their health care. For those with allergic conditions, many new concerns and stressors occur during this important time.

A valuable medical journal article titled "Leaving home: Helping teens

with allergic conditions become independent," outlines many of the considerations to address during this major lifetime transition.* It includes helpful checklists regarding food allergy and asthma preparedness, and a reminder that teen's cognitive development, from concrete thoughts to the formation of logical thinking, emerges at varying rates for different individuals.

(continued on page 6)

Important Epinephrine Updates

Be careful about extreme temperatures

You've probably heard many reminders to bring your epinephrine everywhere so it is always right on hand if needed. Important advice! But you've probably also been warned not to leave it in a car even for a short time, for example, because the medication could be ruined if exposed to extreme temperatures.

Research published just in time for summer provides some reassurance that epinephrine doesn't degrade due to excessive heat or cold as much as had been previously thought. But that applies only to limited freezing or heat exposure, and two small studies comparing refrigerated and unrefrigerated epinephrine found that the refrigerated epinephrine had less degradation.

To help prevent degradation of the epinephrine use an insulated lunchbox, cooler bags or a thermos without ice, or the type of carrier, such as Frio, that diabetics use to keep insulin cool.

New Instructions for Using Epinephrine Auto-Injectors

Labeling changes announced by the FDA this spring include the following:

Hold the patient's leg and keep it steady while you inject the epinephrine. This reduces the risk of injury such as the needle cutting the thigh or becoming stuck in the skin.
When you inject EpiPen® or EpiPen Jr.®, hold the device in place for 3 seconds in the outer thigh. Previous instructions were to hold for 10 seconds.

Food Allergies and Anxiety: Helping a Child Overcome Her Fears

Coping effectively with anxiety is a common challenge for children with food allergies and their parents. In her role as a pediatric psychologist Nancy Rotter has helped many people manage food allergies with more confidence, such as the family described in this article. This narrative is actually a composite of various patient experiences and does not represent one individual. The name used here was created to protect confidentiality.

By Nancy Rotter, Ph.D.

“Molly” is a bubbly, kind, eight year old girl with dairy and peanut allergies. She lives with her mother, father, younger sister (age 5) and older brother (age 11). She was diagnosed with food allergies at 18 months of age, following an episode of vomiting and hives after eating peanut butter. She is the only member of her immediate family with food allergies.

Molly has always done well in school, had many friends and participated in several activities including dance, art classes and girl scouts. While prone to be a worrier by nature, Molly’s tendency to be nervous about separation from her parents and new situations has never significantly impacted her life.

Throughout her life, Molly and her family have managed her food allergies well while participating fully in things that they enjoy including traveling, sailing and eating at restaurants. Prior to age eight, Molly had two non-anaphylactic accidental ingestions. Both episodes resulted in hives and were treated quickly with oral antihistamine medication.

However, during the spring of her third grade year in school, Molly had her first episode of anaphylaxis. Molly’s father was making their usual Saturday morning pancake breakfast,

and accidentally used cow’s milk instead of soymilk in the pancakes. After eating half of a pancake, Molly’s voice was hoarse and she complained that her lips and mouth hurt and that it felt like something was stuck in her throat. Her father



administered epinephrine using her EpiPen®, while her mother called an ambulance. Molly reported that she felt better following the injection, but per her action plan, was taken to the local hospital where she was observed in the emergency room for several hours.

Reaction led to fears

Molly developed significant anxiety and worry following her anaphylactic episode that persisted for a month when her family contacted me for assistance. Since her accidental ingestion, Molly had stopped drinking soy milk, which she typically had with her cereal and drank with dinner, was checking ingredient labels three times prior to eating foods she had always eaten in the past, and washing her hands twice before eating and when she was

worried that she might have touched something that was contaminated with dairy or peanuts.

Additionally, Molly began to bring only apples and carrots for lunch at school, stopped going on playdates and to familiar restaurants and would only allow her mother to prepare her meals. Molly told her parents that she felt nervous about eating and having anaphylaxis again.

I met with Molly and her parents to review her history and current worries. We talked about how Molly’s recent anaphylaxis had clearly triggered her anxiety about having another episode, so she was doing a variety of things to try and prevent this from happening again. Further, Molly’s tendency to be anxious by nature played a role in maintaining her anxiety such that the accidental ingestion “turned up the volume” on her preexisting anxious style.

We talked about a plan to use Cognitive Behavioral Therapy (CBT) and Behavioral Medicine-oriented interventions to work on managing her anxiety, and set goals to help Molly resume eating and engaging in activities that she had done previously.

Molly’s treatment began with psychoeducation about the worry and food allergies. We talked about how it is common for scary events, such as anaphylaxis, to cause children to do what they can to keep them from happening again. We talked about the difference between danger messages and false alarm messages that our brains send us.

Danger messages are sent when the brain perceives a situation to be risky or dangerous to our wellbeing, such as putting one’s hand on a hot stove. Our brains and bodies work

(continued on next page)

Helping a Child Overcome Her Fears (continued from page 2)

quickly and automatically to protect us, such as immediately removing our hand from the stove to prevent us from being burned. However, the brain also sends worry/false alarm messages, when there is no chance of danger, or the chance is very very small. This is similar to when a smoke detector goes off when someone is cooking dinner, but there is no actual fire.

Sometimes mistakes do happen

I discussed with Molly the way in which brains and bodies communicate, such that thoughts (e.g. “what if I accidentally drink milk again?”) can lead to feelings (e.g. worry, including physical symptoms such as stomach pain), which can result in actions/behaviors (e.g. checking ingredient labels multiple times). We also talked about how Molly and her parents were able to avoid anaphylaxis her whole life by following safe practices and still doing all of the things they enjoyed, except for one time. Additionally, we acknowledged that sometimes mistakes happen, which is when medication, such as having epinephrine ready to use, is needed.

Next, we worked on creating an “anxiety hierarchy.” Molly rated her level of discomfort/anxiety about each avoidance behavior on a 0 – 10 scale (0 = no anxiety and 10 = highest level possible). For example, Molly rated her anxiety about reading ingredient labels only once (the goal and method she had followed previously) as 5/10,

but reading labels twice as 2/10. After rating each behavior, we set up a plan for Molly to practice both at home and in session with me. Molly began with the items on her hierarchy that were the least anxiety provoking for her and worked up through the most challenging, until each she had mastered each one. Molly rated her anxiety during each “anxiety exposure” task, and repeated each task until her anxiety rating went to zero.

Prizes for bravery

Molly also earned “bravery points” for each exposure task, and collected points to earn prizes such as a dance party at her house with friends and art supplies. Additionally, to help her with exposure tasks, I taught her cognitive strategies, such as changing her thoughts. For example, instead of telling herself “I might have anaphylaxis if dad makes me lunch,” Molly practiced telling herself things such as “Dad has safely made my meals hundreds of times before. It is really really unlikely that I will have an



Nancy S. Rotter, PhD, is a pediatric psychologist at the Food Allergy Center and the assistant director of the Outpatient Child and Adolescent Psychiatry Service at Massachusetts General Hospital. She is an assistant professor in Psychology, (part-time) at Harvard Medical School. Dr. Rotter regularly treats children with food allergies and eosinophilic gastrointestinal conditions, collaborating with allergists, gastroenterologists, nutritionists, and feeding specialists. She also has a private practice in Newton, Massachusetts.

allergic reaction, but if I do, I can use my medication” and “anxiety can be uncomfortable, but it is not dangerous.”

Relaxation strategies

I also taught Molly some relaxation strategies, such as breathing techniques, for times that she got so nervous that her heart raced during exposure tasks. Molly started with exposure tasks for reducing her hand washing frequency (the easiest for her) and ended with the most challenging, which was eating pancakes that her father made.

Molly made good progress in our work together. Although at times the exposure tasks were hard and took a lot of practice, she gained confidence over the course of treatment and was very proud of her success. We celebrated her success by having pancakes that her father made at our last session.

AAFA New England EDUCATIONAL SUPPORT PROGRAMS

provide you with opportunities to

- Learn from experts • Find resources and gain confidence
- Meet others who share your concerns • Get your questions answered

For upcoming meeting dates and topics:

visit our website (www.asthmaandallergies.org) or call 781-444-7778.

To receive program announcements, send your e-mail address and your location to aafane@aafane.org.



Support groups take a break over the summer months.

These terrific panelists shared their experiences and wisdom at a recent meeting titled “If I Knew Then What I Know Now.”

Breath of Spring 2016

Laughter is the Best Medicine

with Improv Asylum—May 6

The humor of Improv Asylum added to a the fun of a wonderful evening at AAFA New England's annual spring fundraiser. There was great food, a fabulous silent auction, and the satisfaction of supporting programs and services that help people with asthma and allergies live full and healthy lives.

Breath of Spring Committee

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Jan Hanson
Jennifer LeBovidge
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Patricia Pino
Marylee Reister
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Robert Stoker
Mark Uzzell



*Debra Saryan, Executive Director
of AAFA New England,
and Dr. John Saryan.*



*Special thanks to Michele Carrick (right),
President of AAFA New England,
for the beautiful floral arrangements.*



MANY THANKS TO OUR SPONSORS AND DONORS
(see next page, please)

AAFA New England thanks the many sponsors and donors who made our event a success!



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Photos by Carla Uzzell

Sincere thanks to the many others who purchased tickets, and contributed or bid on auction items. Delicious desserts were donated by: Blacker's Bakeshop, Cakes by Erin, Don't Go Nuts, Fancypants Baking Company, Perfectly Free Frozen Treats, Vermont Nut-Free Chocolates

Leaving Home: Support Needed for Older Teens with Allergies

Certainly, for those with potentially life-threatening food allergies, typical adolescent risk-taking behavior is a real potential hazard. Studies have found that over 50% of this age group actually experiments by trying foods to which they have been identified as allergic. Nearly 40% do not carry their epinephrine auto-injector. An even greater percentage does not have it available during sports activities or when they are wearing tight-fitting clothing.

Some teens have not been properly instructed on how to use the device. Many of them do not inform close friends, roommates, or other close companions of the food allergy, either because they feel embarrassed or because of perceived privacy issues. When moving away either independently from their usual hometown/city or while at college, they may not be aware of the location of hospitals or medical facilities.

New living situations can bring exposure to potential allergy and asthma triggers in dorms or apartments. Teens need to be alerted as to what to watch out for and how to communicate with roommates or others about the potential harm to them of cigarette smoke, fragrances, etc.

Conflicts around medication use and other issues may be difficult for both the teen and the parent. For those with asthma, it is very common for teens even while at home to stop their controller medication treatment and rely only on as-needed therapy.

There are many reasons why older teens with asthma don't stick to taking their daily preventive medications, including the cost, their busy schedules, or that they don't



understand the benefit. It is helpful to explain to teens that they are “not alone” in not always following their doctor’s recommendations for medications, but that proper use will provide them better asthma control in the long run. This is particularly true for those who experience exercise-associated symptoms.

Written asthma management plans, including simpler schedules or medications which might be administered just once daily, are very helpful. I find that teens often prefer dry powder inhalers over the use of a metered-dose inhaler with spacer, which can be more cumbersome and time-consuming.

Older adolescents need to be encouraged to continue with regular follow-up visits with their physicians, so they have the opportunity as they mature to receive positive reinforcement and review such issues as the need for ongoing controller medications versus only “as needed” treatment.

I strongly encourage teens and their parents to meet with an asthma educator or a physician before leaving

to live independently or at college to discuss how to avoid asthma triggers, the role of various medications, and the range of food allergy management issues.

* Stukus DR, Nassef M and Rubin M. Leaving home: Helping teens with allergic conditions become independent. *Annals of Allergy, Asthma & Immunology*, 116(5):388-391, 2016
View the article and “talking point” checklists at: <http://www.annallergy.org/>

Taking Asthma and Allergies to College

Visit the “College Tips” section of our website (www.asthmaandallergies.org) for a list of suggestions for meeting the challenges of asthma and allergies. It lists some of the important things to think about and take care of before heading off to college.

You can also download a booklet we produced for a symposium we held on food allergies at college. It includes tips about visiting colleges, choosing a college, and having a successful and safe college experience.

Asking about food ingredients and getting to know the dining services staff is important, but eating is only one part of a student’s experience at college. In addition to finding out about the dining options and policies, it is important to think about how to handle social events and parties, living with a roommate, planning for emergencies, and many other issues that may come up for a student with food allergies.



Frank J. Twarog, M.D., Ph.D., regularly contributes the Research Update column for this newsletter. He is an allergist in Brookline and Concord, MA, and Clinical Professor at Harvard Medical School.

Around AAFA New England

Bring the kids to sing along and learn about living with food allergies!



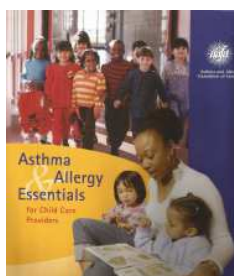
KYLE DINE Concert and EXPO Sunday, October 16, 2016

Time and place to be announced. Check our website or watch your e-mail for details. If you aren't on our e-mail list, sign up at our website: www.asthmaandallergies.org.

Kyle is a performer and educator who writes songs that empower, support and educate children with food allergies and their friends. Kids love him, and families members love the samples and coupons from the EXPO.

"Asthma and Allergy Essentials for Child Care Providers"

That's the title of the workshop we offer to help keep children safe and healthy when they are cared for outside of their homes. A limited amount of grant funding is available to offer the workshops free. Contact us to schedule a program in your area.



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The Asthma and Allergy Foundation of America, New England Chapter, is dedicated to helping people with asthma and allergic diseases, and those who care for them, through education, support for research and an array of services.

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INSIDE THIS ISSUE...

**Food Allergies and Anxiety:
Helping a Child Overcome
Her Fears**

**Leaving Home: Support Needed
for Older Teens with Allergies**
Important Epinephrine Updates

Save these dates:
Kyle Dine Family Concert - Oct. 16
No Biggie Bunch Story Hour - Nov. 5

*Have some fun with people who really "get it," and
help your children feel less alone with their allergies.*

FREE TICKETS!!

**AAFA New England
Family "Meet-Up"**

Lowell Spinners vs.
Brooklyn Cyclones
"peanut-allergy-friendly" baseball game

Sunday, August 21 at 5:05 p.m.
LeLacheur Park - 450 Aiken St., Lowell, MA



For free tickets for your family:
contact AAFA New England by email (aafane@aafane.org) or phone (781-444-7778). (Deadline: Friday, Aug. 19 at noon)

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