

Food Allergy News™



From the moment your child is diagnosed with food allergies, a million questions flood your mind. Will they outgrow this? How will it change their lives? How do we instill the appropriate amount of caution and not cause excessive fear? Having food allergies requires a person to diligently be aware of what they are eating at all times. It can be all-consuming at times, for children and parents. The question is, when does being cautious about avoiding reactions turn into an unhealthy fear of food?

A child or teen with an unhealthy fear of food can display many different signs of disordered eating. Typically when people hear the phrase “eating disorder,” they think about anorexia or bulimia. The incidence of these disorders among those with food allergies is unknown. Little research has been done on the topic.

Most of the time, those with food allergies do not have eating disorders. Disordered eating, however, is much more common among individuals with food allergies and in society in general. This means that one’s relationship with food is moderately to severely disruptive, affecting one’s quality of life.

Developing a healthy relationship with food is a challenge for many people, and one that becomes an even bigger task for individuals with food allergies. Disordered eating can manifest in many different ways, including food phobias or obsessive compulsive thoughts and behaviors with respect to food.

Among the most common fears of those who have life-threatening food allergies

is fear of anaphylaxis or memory of a severe food-allergic reaction. This can be experienced by both the child and the parent. Fear of eating can lead to various different ways of avoiding allergic reactions. Some people choose to eat only what they prepare from raw materials;

others eat foods only if they are prepared by specific people (or one person); and some will not eat outside of the home, or might avoid

social situations where food may be involved, such as play dates and parties.

Many individuals with food allergies are advised to check a label two or three times; once in the store, once when putting the food away, and once before eating it. Compulsive behaviors, such as checking and re-checking labels excessively beyond what is typically recommended, may cause anxiety. Anxiety of a reaction can also cause individuals who are managing food allergies to become distrustful of others, including family members, even in situations where a reaction is highly unlikely.

As a general rule, children learn how to regulate their emotions from their parents. An excessively anxious parent may over-restrict their child’s developmentally appropriate activities. For example, they may avoid social situations that include food.

Helping our children and teens develop safe eating habits without being excessively anxious requires that we instill and model calm, safe, and

continued on page 9

Food Allergies and Disordered Eating Among Children and Adolescents

By Brett Greenberger, M.D. and Emily Greenberger, L.C.S.W.-C.

I N S I D E

2

Heart to Heart

3

Our Family’s Vacation Tips

4

**FAAN Awards
Ingredient Notices
Consumer Alert!**

5

**Epinephrine Auto-injectors:
Training and Coaching Needed
Study Recommends
Children with Food Allergy
Carry Two Epinephrine Doses**

6-7

Allergy-Free Recipes

*Banana-Orange Cookies, Blackberry
Sorbet Parfait, Flank Steak on
Skewers, and more!*

**FAANTastic Divvies Cookie
Contest Winner!**

8

**Answers to Diet Dilemmas
Upcoming Events**

10

Research Update

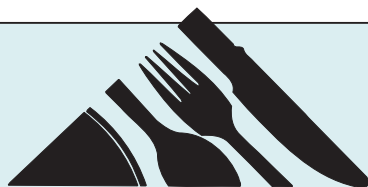
*Food allergy knowledge, attitudes,
and beliefs of primary care
physicians; the natural history
of soy allergy*

11

**Legislative and Advocacy
Update**

12

**Tips for Starting a Support
Group**



Food Allergy News

Julia Bradsher
Publisher

Mary Jo Strobel
Managing Editor

Nancy Gregory
Assistant Editor

Hugh A. Sampson, M.D.
Sally Noone, R.N., M.S.
Medical Editors

Julia Bradsher, President & CEO
Chris Fanning, Chief Financial Officer
Maria Acebal, V.P. and General Counsel
Laura Caldwell, V.P. of Development
Eleanor Garrow-Majka, V.P. of Education & Outreach
Henry McMillan, V.P. of Marketing
Chris Weiss, V.P. of Advocacy & Government Relations
Jennifer Love, Marketing & Media Communications Manager

Operations

Nancy Ammann, Wayne Atkins, Andrea Bartlett,
DeLois Blevins, Veronica Braun, Winifred Brumskine,
Debbie Copan, Jacqueline Dominguez, Tyler Driscoll,
Cindy Durant, Sarah Flores, Darcy Jennings, Michelle Ju,
Stephanie Purman, Michelle Rambajan, Beverly Ryan,
Sarah Sloan, Christopher Soltis, Jarrett Thompson,
Geoff White, Tessa Wolf, Robert York

Board of Medical Advisors

S. Allan Bock, M.D., *Boulder, Colo.*
A. Wesley Burks, M.D., *Durham, N.C.*
Glenn T. Furuta, M.D., *Aurora, Colo.*
John M. James, M.D., *Fort Collins, Colo.*
Stacie Jones, M.D., *Little Rock, Ark.*
Todd Mahr, M.D., *LaCrosse, Wis.*
Hugh A. Sampson, M.D., *New York*
Scott H. Sicherer, M.D., *New York*
F. Estelle R. Simons, M.D., *Winnipeg, Canada*
Steve Taylor, Ph.D., *Lincoln, Neb.*
Robert A. Wood, M.D., *Baltimore, Md.*
Robert S. Zeiger, M.D., Ph.D., *San Diego, Calif.*

The material in *Food Allergy News* is not intended to take the place of your doctor. *Food Allergy News* or the Food Allergy & Anaphylaxis Network will not be held responsible for any action taken by readers as a result of their interpretation of an article from this newsletter. If you have any questions or concerns, ask your physician. Never change your child's diet without the advice or help of a physician and registered dietitian.

Food Allergy News is published 6 times a year by the Food Allergy & Anaphylaxis Network, Inc., 11781 Lee Jackson Hwy., Suite 160, Fairfax, VA 22033-3309. ISSN #1075-4318. Periodicals postage rate paid at Fairfax, Va. POSTMASTER: Send address changes to *Food Allergy News*, 11781 Lee Jackson Hwy., Suite 160, Fairfax, VA 22033-3309.

Our office is open Mon.-Thurs. 9:00 a.m. to 5:30 p.m., and Fri. 9:00 to noon ET. If you have any questions, please call 703-691-3179. To order a subscription, send \$50 in check or money order to the Food Allergy & Anaphylaxis Network. Mastercard, Visa, and American Express are also accepted. All rights reserved. This material may not be duplicated without the expressed written permission of the publisher.

The Food Allergy & Anaphylaxis Network is a nonprofit 501(c)(3) organization. All donations are tax-deductible and help us continue our work.

Heart to Heart

Summer is here! I've been on the road quite a bit this past spring, at four successful Food Allergy Conferences around the country, speaking about food allergies, and raising awareness. And now, many of you will be preparing for a summer vacation or family trip.

One of the four equally important parts of our mission at FAAN is raising awareness. Last month, during Food Allergy Awareness Week, we launched an important public service announcement (PSA), featuring Trace Adkins, that raises awareness to the public about the seriousness of food allergies. FAAN is fortunate to have Trace Adkins, our 2010 National Honorary Walk Chair, as its spokesperson. I hope you have had a chance to see it on your local television station.

Also last month, food allergies made headlines across the country in major newspapers and on national news broadcasts. Much of this attention came from the publication of a review in the *Journal of the American Medical Association* that focused on food allergy and the need for quality studies. FAAN acted swiftly and released a statement, together with the Food Allergy Initiative, renewing the call for federal funding for studies on prevalence, diagnosis, and treatment of food allergy. This news release can be viewed on our website's Media Center. In this section, you'll also find a selection of the most recent news articles focusing on food allergy.

I am pleased to let you know that FAAN has three new prominent Ambassadors Who Care. Journalist and author Janice Lieberman, actor Frank Dicopoulos, and reporter Brian

Thompson have joined us in our efforts to raise awareness about food allergies. You can read their profiles in the Media Center.

In the Spring, we also completed our inaugural Food Allergy Leaders Summit. We brought together approximately 120 support group leaders and Walk chairs to spend a day together learning from one another. Sessions focused on developing skills for talking to the media, strategies for organizing their support groups and Walks, tips on how to advocate in your local area for food allergies, and other important topics.

This issue of *Food Allergy News* is filled with information on managing food allergies, including tips for vacationing with children and for traveling adults on the road. There's also important information about proper training for using epinephrine auto-injectors and avoiding accidental injections.

In the coming months, we have almost 50 Walk for Food Allergy events scheduled around the country. I hope to see you at one of the Walks as we raise awareness and important funds to support the work that we are doing here at FAAN. Check out the Walk website (www.foodallergywalk.org) and register today.

Please let us know how we can help you and your family. I hope you have a very safe and enjoyable summer!

We are with you always,

Julia Bradsher

Our Family's Vacation Tips

By Christina Black

We are a family of four: dad, mom, older daughter, and younger son. Our son Robbie was diagnosed with a peanut allergy as a toddler. Since then he has reacted to other legumes, such as chick peas, lentils, and peas.

We have enjoyed fun trips to Disney World, Boston, Chicago, and various beaches. We are fortunate that our son has not had a food-allergic reaction on any of these trips, thanks to good planning, helpful workers, and some luck.

Here, I'd like to share my family's tips for planning a vacation with food allergies.

Choose a good location. We rule out isolated beaches 30 minutes from anywhere. Or bayside resorts accessible only by boat. For my own peace of mind, we don't go there. I like a modern hospital and EMS service nearby. A remote location could work for a more adventurous mom, but it is just not for me.

Be prepared for anything! In our family, someone is always getting pink eye, a fever bug, or a finger stuck in a door. Next time, it could be an allergy emergency. So we bring our allergy stuff!

- two or more epinephrine auto-injectors that have not expired
- a doctor's letter explaining why Robbie needs epinephrine
- antihistamine
- inhalers
- wipes
- lots of safe snacks
- chef cards listing the foods Robbie must avoid

Plan meals in advance. When we are traveling, we try to rent a condo instead of staying in a hotel. Having a small kitchen lets us save money, feed the kids more quickly, and better manage ingredients in Robbie's food. We once found a spoon with caked-on peanut butter in the silverware drawer, so we definitely take a look around the condo's kitchen before we start cooking!

Dine out wisely. You don't want to find yourself wandering around a strange location looking for a restaurant where your family will be comfortable eating. Try to find two or three restaurant options in advance, and check the menus. Call ahead and talk to the manager about how the restaurant can accommodate someone with a food allergy.

Trust your instincts. If you talk to restaurant staff and still don't feel food allergies are understood, this restaurant may not be the place to eat. Keep walking!

Remember, it is okay to go with an old standby. Robbie has eaten at some familiar fast food restaurants in the midst of wonderful food courts full of diverse ethnic treats. Experimenting with foods is just not part of Robbie's vacation experience.

Let your child do the talking. Vacation is a fun time and can also be a learning time. Some day, your child will prefer eating out with their friends instead of the family. Start getting them ready now! Let your child begin the allergy conversation with food service staff. A shy child may find it easier to hand the server or manager a chef card that explains his

allergies, knowing you are right there to support them and clarify any issues.

If you are planning a vacation with your family this summer, we hope you have a super time!

Christina Black has been a member of FAAN since 2003.

Travel Tips

We asked members of FAAN's Facebook group for their best tips geared toward adults managing food allergies. We got some great advice to share:

- ◆ For work-related travel, send a reminder to the conference coordinator about your food allergies so that accommodations can be made for meals.
- ◆ Pack your own snacks and scout out the closest grocery store to your hotel, and request a room with a refrigerator and a microwave, if possible.
- ◆ If you're traveling abroad, have a card that explains your allergies translated into the local language. Bring extra copies!
- ◆ Use an online reservation service for restaurants and be specific about your allergies.
- ◆ Attach a laminated tag to the outside of your briefcase or travel bag that explains anaphylaxis and what to do if a reaction occurs.

FAAN Awards

We are pleased to share with you the results of this year's Mariel C. Furlong Awards for Making a Difference, given out annually to individuals, schools, and corporations that have made a significant impact on the lives of individuals with food allergies, as well as winners of the Second Annual Grandparent Awards and FAAN's Special Achievement Awards.

Congratulations to all of the winners!

Community Service/Support

Group: Kathy Franklin and Caren Sanger, Parents of Asthmatic and Allergic Children (PAAC), New York, N.Y.

Angie Norton, Phoenix Allergy Network (PAN), Chandler, Ariz.

Andria Youngberg, NC FACES (Food Allergic Children Excelling Safely), Raleigh/Cary, N.C.

Camp: Ed Collins, The Center for Courageous Kids, Scottsville, Ky.

Food Industry: Bruce Gibbens, Bonsall, Calif.

Health Professional: Lawrence Larson, D.O., Tacoma, Wash.

Mary Beth Feuling, R.D., Wauwatosa, Wisc.

School: St. Stephen ECD & Preschool, Inc., St. Louis, Mo.

School Principal: Rick Hanebutt, Hope Lutheran School, Shawnee, Kan.

School Nurse: Cathy Miller, R.N., Henrico, Va.

School Dining Services: Brenda Klamert, R.D., Oconomowoc, Wisc.

School Staff: Elaine Goodwin, R.N., Yorktown Heights, N.Y.

Timothy Rourke, Woodbridge, Conn.

Grandparent Award: Elinor Black, Marshfield, Mass.

Youth Special Achievement

Award: Hunter Hampton, Osprey, Fla.
Emily Zauzmer, Dresher, Pa.

Special Achievement Award:

Michael Pistiner, M.D., Leominster, Mass.

Campbell Soup Company, Camden, N.J.

Dr. Pistiner was recognized for his advocacy work, and Campbell Soup Company was recognized for its allergen labeling system.

Consumer Alert!

Allergens continue to show up in places where you wouldn't expect them. New products, many of which are "improved" or "healthier" versions of products that you may buy on a regular basis, are constantly appearing on grocery shelves. As always, remember to read the label, every time. Be aware that some beverage brands that you drink on an everyday basis could also have versions that are enhanced with whey (milk) to include protein in them. We recently heard from a FAAN member who bought a new pasta that had several surprise ingredients not normally associated with a pasta.



If your home has a yard or a garden, and someone in your family has a peanut allergy, be mindful that some mulch may contain this allergen. Be aware that this type of product is exempt from labeling regulations, so you may not see peanut listed on the bag. Call the company with your questions so that you can select mulch that is made free of peanut shells.

Ingredient Notices

Gerber® Graduates® for Toddlers Cinnamon Graham Animal Crackers' product labeling has changed to include milk in the list of ingredients. Product packaging with this change will be arriving into the market in late April to early May 2010.

Gerber® Graduates® for Toddlers Sweet Potato Puffs - Puffed Grains with Real Vegetables' product labeling has changed to include soy lecithin in the list of ingredients. Product packaging with this change will be arriving into the market in late June to early July 2010.

For more information, contact the Gerber Service Center at 800-443-7237.

Hormel Foods has reformulated its Hormel Chili with Bean to include soy. Textured Vegetable Protein, which is derived from soy, will now be included on labels within the ingredient listing as "Textured Vegetable Protein (Soy Flour)." For more information, contact Hormel Foods Consumer Response at 800-523-4635.

Epinephrine Auto-injectors: Training and Coaching Needed

By F. Estelle R. Simons, M.D.

Epinephrine auto-injectors provide life-saving pre-hospital treatment for people who experience anaphylaxis. Antihistamines and other medications used for the treatment of anaphylaxis cannot be substituted for epinephrine because they do not prevent or relieve upper and lower airway obstruction, nor low blood pressure and shock.

Unintentional injection of epinephrine from auto-injectors sometimes occurs. Typically, this happens in the home, and involves injection of epinephrine into the finger, thumb, or hand, rather than the intended site of injection, which is the middle of the outer side of the thigh.

In a recent publication in *The Journal of Allergy and Clinical Immunology*, allergy/immunology specialists and emergency medicine specialists studied the number of unintentional injections from epinephrine auto-injectors that were voluntarily reported to the American Association of Poison Control Centers, and to the Food and Drug Administration's MedWatch program.

We found that 15,190 unintentional injections were reported to U.S. Poison Control Centers from 1994 to 2007, and that the number of unintentional injections increased steadily year by year, especially from 2003 to 2007. Despite this, we think that under-reporting probably occurred because telephone calls to Poison Control Centers are voluntary. An important finding was that where management of injuries from these unintentional injections was documented, 29% of the patients required treatment in an emergency department.

From voluntary reports to the MedWatch program, we obtained additional information about how the unintentional injections occurred. Forty percent of them happened when someone was either trying to inject themselves during an allergic reaction, or trying to inject another person having an allergic reaction. Thirteen percent occurred when a person was trying to figure out how the epinephrine auto-injector worked. Eight percent occurred during an epinephrine auto-injector training or demonstration session. Some of the unintentional injuries also occurred when a child found an epinephrine

auto-injector and began to play with it, or when a person was trying to dispose of an epinephrine auto-injector.

Based on our findings, we have developed a surveillance instrument suitable for trial use in Poison Control Centers so that information about unintentional injections of epinephrine can be collected in a systematic way. We anticipate that this will help to obtain further information about the "lost dose hazard," which occurs when the epinephrine dose intended for a patient with anaphylaxis is either completely lost when it is

continued on page 9

Study Recommends Children with Food Allergy Carry Two Epinephrine Doses

A study in the April issue of *Pediatrics* has garnered attention in the media for its conclusion that children with food allergies should always have two epinephrine auto-injectors with them, rather than one. This is believed to be the largest study of the cause and treatment of food-induced anaphylaxis in children.

Researchers used data from food-related allergic reactions involving children who went to two Boston hospital emergency rooms from 2001-2006. Researchers learned that 41% of the children had a known allergy to the offending food, and 40% owned an epinephrine auto-injector.

The study found that 12% of children who were administered epinephrine for anaphylaxis required more than one dose, and 59% of those children received the second dose within an hour of the first dose.

Researchers concluded that food-related anaphylaxis is under-recognized and inadequately treated in the emergency room setting – just 13% of the cases that met the criteria for anaphylaxis were assigned a diagnosis during discharge that included the term "anaphylaxis." They also noted that children who live in settings where emergency care may not be readily available, and who are at risk for food-related anaphylaxis, are advised to carry multiple doses of epinephrine.

Recognizing the cost associated with carrying a second dose of epinephrine, the study's authors said cost-saving approaches, such as having a non-student-specific dose of epinephrine available at schools and child care facilities, should be given consideration.

Allergy-Free Recipes

In this issue, we're featuring some tasty dishes that are perfect for a summer barbecue. Company's coming over? No problem – we've got a recipe for dressing up a summer dessert – check out our Blackberry Sorbet Parfait.

Key to Symbols:

M, Milk-free; **E**, Egg-free;
W, Wheat-free; **P**, Peanut-free;
S, Soy-free; **N**, Nut-free

Blackberry Sorbet Parfait

M, E, P, N

1 cup water
 1 cup sugar
 1 lb. blackberries, thawed if frozen
 2 T. lemon juice

In small saucepan, bring water to a boil. Remove from heat, and stir in sugar until dissolved. Pour the sugar syrup into heatproof bowl and chill in refrigerator, about one hour. Place blackberries in a blender or food processor and purée. Add purée to chilled sugar syrup and then strain to remove seeds. Add lemon juice. Cover and refrigerate until the mixture is thoroughly chilled.

Pour mixture into 8-inch pan, cover with plastic wrap, and place in the freezer. When mixture is partially frozen, spoon into bowl and blend with mixer at medium speed until smooth but still frozen. Return mixture to pan. Cover and freeze until firm.

To make sorbet parfait, layer spoonfuls of sorbet into glass ice cream cups with layers of crumbled cookies. Use our Banana Orange Cookies or your favorite allergy-safe cookie. Repeat layers at least twice and top with a sprinkling of your cookie pieces.



Banana Orange Cookies

M, E, P, N

2 cups quick oats
 2 cups flour
 3/4 tsp. baking soda
 1/2 tsp. salt
 1 2/3 cups mashed, ripe banana (about 3 large bananas)
 3/4 cup milk-free margarine
 1/2 cup orange juice
 3 T. water, 3 T. oil, 2 tsp. baking powder, mixed together
 2 tsp. vanilla
 1 tsp. grated orange peel
 3/4 cup raisins

Preheat oven to 350°. In medium bowl, combine oats, flour, baking soda, and salt. Set aside. In large bowl, beat bananas, margarine, and orange juice until smooth. Add dry ingredients; mix well. Add water, oil, and baking powder mixture; vanilla; and orange peel; mix well. Stir in raisins.



Drop dough by rounded tablespoonfuls onto ungreased cookie sheet.

Bake 20 to 22 minutes or until light golden brown. Cool 2 minutes on cookie sheet; remove to wire rack.

Icing

3/4 cup powdered sugar
 2 T. orange juice
 2 T. water
 1 tsp. grated orange peel

Combine ingredients over medium heat for 3 to 4 minutes; drizzle over cookies. Store tightly covered.

Flank Steak on Skewers

M, E, P, N

Marinade

1/3 cup soy sauce
 1/4 cup olive oil
 1/4 cup honey
 2 cloves garlic, minced
 2 T. red wine vinegar
 1/2 tsp. black pepper
 1/2 tsp. ginger, minced
 1 lb. flank steak

In small bowl, whisk together soy sauce, olive oil, honey, garlic, red wine vinegar, pepper, and ginger. Place steak in glass

dish or large plastic bag; pour marinade over steak and cover or seal for several hours or overnight. Preheat grill; cut flank steak, across the grain, into 1-inch strips. Thread strips of steaks onto skewers and place on grill (or broiler). Grill about 3 minutes per side or until steak is cooked to desired degree.

Note: Most commercial soy sauces contain wheat, however, read the label for tamari soy sauce, which is usually wheat-free. If you cannot find this type at the grocery store, search online for where to purchase.

Easy Grilled Potatoes

M, E, P, N, W

4 medium potatoes, diced
1 small onion, sliced
2 T. olive oil
2 cloves garlic, minced
1 T. milk-free margarine, cut into 4-6 cubes
pepper
salt

Drizzle olive oil onto a large sheet of heavy-duty foil (make sure that sheet is large enough so that potatoes fit on half of sheet). Add potatoes to one half of foil, then add sliced onions. Spread garlic on top of potatoes and onions. Add pepper and salt to taste, then top with milk-free margarine.

Fold the foil to cover potatoes until you have created a tight seal. Place potato packet on a preheated grill. Grill for 20 to 30 minutes, flipping foil packet after 10 minutes, or until potatoes are tender. You may also bake these in a 425° oven for about 25 minutes.



Pear Pie

M, E, P, N

3/4 cup sugar
3 T. tapioca
2 T. lemon juice
2 T. milk-free margarine, cubed
1/2 tsp. cinnamon
1/4 tsp. nutmeg

Looking for more recipes?

Check out the recipe database in the Members Area of our website! Log into the website, then click on the Members Area tab on the upper right corner. You'll find more simple allergy-friendly recipes for each course. You can also submit recipes and rate ours!

Melon Jigglers

M, E, W, P, S, N

2 cantaloupes or honeydew melons
2 3-oz packages of gelatin, any flavors

Prepare gelatin according to package instructions in two separate containers. Cut melons in half, scooping out seeds in the center. Make a thin horizontal slice from the bottom of each melon half so that each melon half can stand upright. After gelatin has cooled, pour into a measuring cup with a spout and pour into melon halves.



Refrigerate until set, at least three hours. To serve, cut melon into wedges.

1/4 tsp. salt
6 large ripe pears, peeled and diced
Crust
2 1/2 cups flour
1 T. sugar
1/2 tsp. salt
3/4 cup milk-free margarine, chilled and cut into 1/4-inch slices
1/4 cup shortening, chilled
5 to 7 T. ice water

Preheat oven to 400°. In large bowl, combine sugar, tapioca, lemon juice, margarine, cinnamon, nutmeg, and salt. Add pears and combine; set aside.

To prepare crust, in medium bowl, stir together flour, sugar, and salt. Cut in margarine and shortening until mixture resembles coarse meal. Add water 1 T. at a time, pressing dough with a fork until it holds together. Gather dough into ball and divide in two, making one portion slightly larger than the other. Wrap the smaller ball in plastic wrap and refrigerate.

On a lightly floured surface, roll out larger ball to about 1/8 inch thick (it should be big enough to cover the pie plate with 2 inches extra). Fit crust into 9-inch pie plate. Trim crust and fold edges over. Add

pear filling to pie plate. Roll out smaller dough ball and cover filling. Seal edges and cut slits near the center, or create a lattice top. Bake 50 to 60 minutes. Cool on a wire rack.

FAANTastic Divvies Cookie Contest Winner!

Congratulations to Elizabeth Ilson of Tarpon Springs, Fla., whose Double Chocolate Brownie Bites proved to be scrumptious! Elizabeth's cookies beat out more than 260 other entries and will be developed and commercially produced by Divvies! As the grand prize winner, Elizabeth won two nights' stay and waterpark passes for up to four individuals at a Great Wolf Lodge Resort in the U.S. Samples of Elizabeth's Double Chocolate Brownie Bites will be available at many of FAAN's Walk for Food Allergy events starting in August.

Thank you to everyone who submitted recipes. We look forward to another successful contest next year!

Answers to Diet Dilemmas

"My son is 18 months old and allergic to oats, milk, beef, soy, corn, rice, and peanuts. His major issue is that he does not gain weight and continues to lose weight. Could this all be allergy-related?"

Lori Enriquez, R.D., answers:

Having a food allergy typically is not the primary cause of poor weight gain or weight loss, but because of the need to avoid multiple foods, the diet may not be adequate and result in poor weight gain and growth. There is a rapid period of growth and development from birth until 2 years of age. Weight loss or weight

gain occurs depending on how many calories are consumed compared with how many are calories are needed. It sounds like your son's growth chart is not progressing as would be expected. Most likely, your son is not taking in enough calories.

Children with multiple food allergies are at higher risk for inadequate nutrition and should be monitored closely. These children may need nutritional supplements or special formulas. I would recommend you talk with your health care team about your concerns and ask for a referral to see a registered dietitian who is familiar with restricted diets.

Without knowing your son's current dietary intake and growth parameters, it is difficult to give specific nutrition advice, but I will provide some general suggestions to consider.

Young children and toddlers need two to three snacks per day along with three meals; nutrition comes from both drinks and table food. For children one year and older who drink milk or a milk substitute, 16-24 oz. a day is the typical recommendation for minimum to maximum goal amounts.

At 18 months of age with multiple food allergies, including milk, soy, and rice and poor weight gain, your son may benefit from an age-appropriate elemental formula if he is not already on one. These formulas provide calories, protein, fat, carbohydrates, and added vitamins and minerals. There are several flavors, which may help with acceptance of the formula.

For table foods, your son should be able to include items such as a variety of fruits and vegetables, chicken, turkey, lamb, pork, beans, pasta, tapioca, wheat products, and alternative grains such as quinoa, and amaranth. For added calories, refined oils can be used when cooking, and jelly and syrup can be added to foods. Of course, always check the labels of any foods first to make sure they do not contain any of your son's allergens.

You may want to discuss foods your son has not tried before with your health care team and introduce them one at a time. Remember to encourage feeding development by encouraging your child to feed himself and to encourage a variety of food textures. Food allergy cookbooks can be a great

continued on page 9

Upcoming Events

13th Annual Food Allergy News for Kids Poster Contest

Remember, the deadline for entries for FAAN's annual poster contest is June 11! Visit www.faankids.org for more details.

Fifth Annual Teen Summit

Mark your calendars, the Fifth Annual Teen Summit will be held Oct. 22-24 in Baltimore at the Sheraton Inner Harbor this year. This year's summit is open to youths ages 11-20 with food allergies and their siblings ages 11-20. For more information or to register, visit www.faanteen.org.

2010 Walk for Food Allergy: Moving Toward a Cure

Here is a list of some upcoming Walks. Check out www.foodallergywalk.org to register, volunteer, or view a complete schedule.

Aug. 14 – Buffalo, NY	Aug. 21 – Indianapolis, IN	Aug. 28 – Nashville, TN
Aug. 15 – Denver, CO	Aug. 21 – Minneapolis, MN	Aug. 28 – Portland, OR
Aug. 15 – Seattle, WA	Aug. 28 – Charleston, SC	

Heart of FAAN Ambassador

Nominations for the 2011 Heart of FAAN Child Ambassador are now open! Supporters of FAAN who are between the ages of 3-11 and who have a food allergy are eligible to become the next child ambassador, who will join FAAN in helping to raise food allergy awareness next year. Nominations will be accepted until the end of the year, and are taken online for a donation of \$100 per entrant. The votes, accepted online for \$10 each, will be tabulated at the end of the year. Visit www.foodallergyevents.org for more information.

Food Allergies and Disordered Eating Among Children and Adolescents

continued from page 1

cautious practices regarding what, when, where, and how we eat.

As parents of children with life-threatening food allergies, we want them to experience all the things that non-allergic children experience. Therefore, it is important to provide our children with age-appropriate social situations to help them build confidence and self-esteem with regard to managing food allergies.

It is important that parents strive for a healthy caution rather than becoming overly anxious or afraid of a reaction, despite appropriate measures to avoid food allergens.

When should you seek help? When is it time to talk to someone about the possibility of your child having disordered eating behaviors? If you observe any eating behaviors that are negatively impacting your child's quality of life, or if your child is purposely avoiding activities because of food, or refusing to eat in public, talk to your child. Share your concerns about their behaviors, and listen to their concerns.

If you or your child is feeling overwhelmed, it would certainly be appropriate to speak with a professional. If your child is restricting foods to the point of failure to thrive, or shifting on the growth curve or experiencing significant weight loss, it would be important to share your concerns with your allergist and/or pediatrician.

You can empower your child to choose safe foods by creating labels that

indicate, for example "This Food is Safe for Jane." Reassure your child that foods served to them by you, or a trusted adult you designate, are safe for them, and that caregivers know how to keep them safe. Show trust and confidence in others and in the foods you serve your child. When dining out, model calm, safe ordering practices such as speaking to a chef or manager prior to ordering and alerting the server of ingredients that must be avoided.

Our children learn from us every day. They look at the expression on our faces; they read our tone of voice. It is our job as parents to teach our children that while life with food allergies may be hard, it does not define who they are. It is a part of them, not all of them.

If you feel that your child is experiencing an overwhelming amount of anxiety with respect to their food allergies, talk to your child's pediatrician or a mental health counselor. There are many counselors who treat anxiety and children with food allergies. Always know that you are not alone in this, and neither is your child.

Dr. Brett Greenberger is a practicing Child and Adolescent Psychiatrist in Maryland. He is the Associate Medical Director of MSA: The Child and Adolescent Center in Columbia, Maryland and the Medical Director of Jewish Community Services in Baltimore. He is also an Adjunct Professor at the University of Maryland School of Nursing, while acting as a Consulting Psychiatrist at Howard County General Hospital.

Emily Greenberger, LCSW-C is a clinical social worker practicing school counseling in Maryland. She provides individual and group therapy for children in preschool through 5th grade as well as parent education and support in her school. Emily is an active member of FAAN, chairing the Greater DC/Baltimore Walk for Food Allergies from 2007 to 2010.

Emily and Brett have three children, two of whom have food allergies.

Answers to Diet Dilemmas

continued from page 8

resource. There are several available from FAAN.

A child with multiple food allergies can have an adequate diet. Specific dietary recommendations should be made considering each child's food allergies, age, growth, food preferences, and activity level. Again, discuss your concerns with your health care team and consult with a registered dietitian for more specific advice.

Lori P. Enriquez, M.P.H., R.D., C.S.P., C.H.E.S., L.D.N. is a senior preventive health coordinator with Independence Blue Cross, and has an allergy to peanuts.

Epinephrine Auto-injectors: Training and Coaching Needed

continued from page 5

unintentionally injected into another person, or partially lost when it is unintentionally self-injected into a small body space such as a finger, from which absorption is delayed.

Healthcare professionals, patients, and caregivers need to be vigilant in learning how to use epinephrine auto-injectors. Regular training and coaching sessions are needed. Increased public awareness of the important role of epinephrine auto-injectors in the first-aid treatment of anaphylaxis is also needed. The design of epinephrine auto-injectors is being improved in order to minimize unintentional injections and the injuries they cause.

F. Estelle R. Simons, M.D., F.R.C.P.C., is a professor in the Department of Pediatrics & Child Health and the Department of Immunology at the University of Manitoba, and a member of FAAN's Medical Advisory Board.

Research Update



Food allergy knowledge, attitudes, and beliefs of primary care physicians

Gupta RS, Springston EE, Kim JS, Smith B, Pongracic JA, Wang X, Holl J. *Pediatrics*, 2010; 125:126-32.

This study aimed to measure the level of food allergy knowledge among pediatricians and family physicians and concluded that this knowledge could only be rated as fair. The study used the Chicago Food Allergy Research Survey for Pediatricians and Primary Care Physicians as the basis for this study, which gathered responses from 407 physicians, 83% of which were pediatricians. Of the responding physicians, 99% indicated that they had patients with food allergies. Among the findings were that 61% of the respondents answered knowledge-based items correctly, with pediatricians scoring higher (62%) than family physicians (54%).

But several weaknesses were identified. Less than 25% of the physicians were aware that oral food challenges could be used to diagnose a food allergy. Less than 30% felt comfortable interpreting lab results to diagnose a food allergy, and just 22% felt that their medical training prepared them adequately to care for patients with food allergies. Half of the respondents correctly identified the dosage of epinephrine based on a child's weight. Less than one quarter of respondents said that milk-based yogurts and cheeses were safe for children with IgE-mediated milk allergy.

Strengths included knowledge that the flu vaccine is not safe for children allergic to egg (80% correctly answered this question), and the knowledge that there is no cure for food allergy (also 80%).

In a question designed to measure food allergy perceptions, respondents were asked to select the single most important step to improve the lives of individuals with food allergies. The responses varied widely: promoting public awareness (33%), identifying the cause of food allergy (30%), developing a cure (19%), improving treatments (13%), and promoting educational programs in school (5%).

Researchers noted that the opportunity for improvement exists, "acknowledged by the respondents' own perceptions of their clinical abilities in the management of food allergy." The study authors also noted that pediatric and family practice training does not typically provide formal food allergy training.

Editor's note: to find a board-certified allergist, visit www.aaaai.org or www.acaai.org.

The natural history of soy allergy

Savage JH, Kaeding AJ, Matsui EC, Wood RA. *J Allergy Clin Immunol*, 2010;125:683-86

This study closely examined the natural history of soy allergy to better understand the rate at which an individual develops tolerance to soy, and to try to determine what factors might predict when the allergy is outgrown.

Approximately 0.4% of children are allergic to soy, an allergy that is generally known to be outgrown at an early age (researchers have suggested this occurs in preschool years). But earlier studies about soy allergy have used only smaller groups – these investigators used a larger cohort to make their conclusions.

Using records of patients from the Johns Hopkins Pediatric Allergy Clinic, reviewers identified 133 patients with

soy allergy, those with a history of an IgE-mediated allergic reaction to soy and evidence of soy sensitization.

This review supported the widely-held assertion that soy allergy is likely to be outgrown, but found that this tolerance is not achieved at an early age, contrary to what had been previously thought. The study found that 69% of the patients had outgrown their allergy by the age of 10.

Researchers identified a "significant relationship" between soy IgE levels and the rate at which soy allergy is outgrown. The more that a child's IgE level has increased, the more likely that he or she is to have a persistent soy allergy. Patients with a soy IgE level of 50 kUA/L or more were likely to develop tolerance at a slower rate. For patients with a peak soy IgE level of this number, the median age at which the patient developed tolerance was age 10 compared with age 5 in patients with a peak soy IgE level of less than 5 kU/L.

Of note, the researchers identified a group of patients within the cohort with late-onset soy allergy – their symptoms began after soy had been part of their regular diet. Because soy allergy is generally thought to be an early-onset allergy, this suggests there are two soy allergy phenotypes, with the late-onset variety possibly related to either birch pollen cross-reactivity or persistent peanut allergy, according to the study. Seven of the 11 patients with late-onset soy allergy also had peanut IgE levels of greater than 100 kU/L at their last appointments.

While this was the largest study of the natural history of soy allergy to date, the authors noted that further studies would be necessary to validate these results.

Legislative and Advocacy Update

State Issues

Students Carrying Prescribed Epinephrine at School

Legislation that would allow students to carry their prescribed epinephrine at school has been enacted in Mississippi (S.B. 2393), and is still pending in Pennsylvania (H.B. 1336). The new law in Mississippi applies to all schools (public, private, and parochial). The bill in Pennsylvania was passed by the House in March, and is now being considered by the Senate.

Other State Legislation

Legislation in Pennsylvania (H.B. 1148) calls on the Pennsylvania Department of Education (PDE), in collaboration with newly created advisory health councils, to develop food allergy management guidelines for schools, and to publish the guidelines on the PDE website by January 2011. This legislation successfully passed the Pennsylvania House in March, and is being considered by the Pennsylvania Senate.

A bill in Massachusetts (H.B. 4569) would require all new applicants for a school bus driver's license (as well as those renewing their applications) to successfully complete a basic course in first aid, which would include training on administering an epinephrine auto-injector.

Legislation in New York (A. 7622/S. 5925) would require proprietors and employees of restaurants to be educated about the dangers of severe food allergy. This information would include the need to inform customers of the presence of allergens in menu items, the possibility of cross-contact during food preparation, the symptoms of allergic reactions, and the need for

rapid response to allergic emergencies. The legislation has already been approved by the Assembly, and is now being considered by the Senate.

In Pennsylvania, H.B. 45 would require training programs designed to prepare candidates for restaurant certification exams to include training on food allergies via a video and written materials.

Epinephrine and Emergency Medical Services (EMS)

Beginning in May of this year, all ambulances in New York State are required to carry epinephrine (along with defibrillators), in accordance with a new policy issued by the state's Bureau of EMS.

Previously, only advanced life-support (ALS) ambulances were required to carry epinephrine, while basic life support (BLS) vehicles were not. BLS vehicles can meet the new requirement by stocking adult and pediatric auto-injectors.

Insurance Coverage for Infant Formula

Legislation that would expand insurance coverage for amino-based infant formulas that are medically necessary due to eosinophilic disorders has been introduced in New York (A. 10450 and A. 2188/S. 628) and New Jersey (A. 400 and S. 1110).

National Issues

Collaboration with Federal Partners

In March 2010, FAAN participated in a workshop hosted by the USDA's Food and Nutrition Service, entitled "Food Allergies: Trends, Issues, and Opportunities." During the

workshop, presentations were given by representatives from a multitude of national and governmental organizations, including FAAN, the Centers for Disease Control (CDC), the Food and Drug Administration (FDA), the National School Boards Association (NSBA), and the National Association of School Nurses (NASN). FAAN was invited to speak and present on consumer issues, FAAN programs, and parental perspectives.

FAAMA

We are still optimistic about passage of FAAMA, The Food Allergy and Anaphylaxis Management Act (H.R. 1378 in the House, S. 456 in the Senate). FAAMA calls on the federal government to create voluntary food allergy management guidelines for schools, and provides incentive grants to local education agencies (school boards) who embrace the guidelines. The legislation has bipartisan support from more than one-third of U.S. senators, along with 84 members of the U.S. House of Representatives.

For questions on any of these legislative/advocacy issues, send an e-mail to cweiss@foodallergy.org.

FAAN's Monthly Update

You asked us, and we're delivering! Many of you have told us you'd like to hear more from us. We've recently launched the FAAN Monthly Update, an e-mail communication that keeps you in the loop on FAAN programs and activities. Sign up by visiting www.foodallergy.org/page/email-signup.

Tips for Starting a Support Group

- ◆ Partner with another adult or parent who is managing food allergies, since starting a support group is a commitment.
 - ◆ Create a name and a mission statement, and establish general guidelines for your meetings.
 - ◆ Define your region (city, surrounding city, counties).
 - ◆ Ask a local allergist to serve as a medical advisor, and form an affiliation with a prominent area hospital.
 - ◆ Find a meeting place (such as a local hospital).
 - ◆ Plan meeting schedules and agendas with topics in advance.
 - ◆ Ask permission to post a flier announcing your first meeting, along with details, in the offices of allergists, pediatricians, and school nurses, as well as health food stores, public libraries, and child care facilities.
 - ◆ Create a lending library for members of your group, offering a collection of books, DVDs, and other educational materials.
 - ◆ Set up an official e-mail address so that your support group members can contact you. You may even want to create your own website.
 - ◆ Enlist volunteers to help out in areas where they feel comfortable.
 - ◆ Contact FAAN for official recognition of your support group; your group's information can then be listed on our website.
- For more information on how to start a support group, contact Beverly Ryan at bryan@foodallergy.org.

New FAAN Events Website Debuts

FAAN has launched www.foodallergyevents.org, a website that will make personal fundraising for food allergy research and education easier than ever. This secure website allows you to turn any event into a fundraiser, providing you with a secure online web presence to accept donations and send invitations to your event.

This website is also the go-to place for information about FAAN events such as the Golf Classic and the Heart of FAAN Ambassador program.



The Food Allergy & Anaphylaxis Network

11781 Lee Jackson Hwy., Suite 160
Fairfax, VA 22033-3309
◆ fann@foodallergy.org ◆ www.foodallergy.org

ADDRESS SERVICE REQUESTED

Periodicals:
Postage Paid
at Fairfax, VA