

ASTHMA & ALLERGY

BULLETIN

ASTHMA AND ALLERGY FOUNDATION OF AMERICA • NEW ENGLAND CHAPTER • VOL. 25, No. 2

From the Executive Director

Dear Friends,

This issue of the Bulletin is full of information to help you and your family. When AAFA New England was formed in 1979 our mission was to control and cure asthma and allergies through education, public awareness, advocacy and support of research. Today, since there is still no cure for these diseases, our work continues. But we have many reasons to be grateful, as we have helped thousands of people every year to enjoy healthier, more fulfilling lives.

However, I must also report that AAFA New England is facing serious financial challenges. Like all non-profits, the economic downturn has hit us hard. We have trimmed our budget and reached out to new funding sources, but we simply cannot carry on without your help. As you reflect on the newsletter you are reading, the personal help you receive when you call us, or the group you may attend, please consider joining or renewing your membership to help us keep these services for New Englanders who need our help. Join today and receive a free book (see pages 7 & 8).

Elaine Erenrich Rosenburg
Executive Director

Stop the FLU from Getting YOU!

People with asthma are at increased risk for serious complications from the flu. Contact your doctor or local health department to make sure you and your family members get protected against both seasonal influenza and the H1N1 ("swine flu") virus.

People with a history of allergy to eggs or egg products should not receive flu vaccine without first consulting their physician.

Milk Allergy May Be "History" For This Brave Massachusetts Boy

Brett Nasuti's multiple severe food allergies have brought him unexpected fame in recent months. He is the first person to complete a trial of a therapy that could eliminate the threat of severe reactions that he and his family have lived with almost all his life. Brett is part of a study underway



at Children's Hospital Boston using a combination of medication and "oral immunotherapy," to desensitize children with milk allergy so that they may tolerate dairy products.

Media-savvy eleven-year-old Brett is almost as enthusiastic about helping to find a cure and increase awareness about food allergies as he is about his dream of sharing a pizza or ice cream with his friends. He has been interviewed by newspaper and TV reporters and followed by a film crew from Children's Hospital, which will feature his dramatic story in its magazine and on-line health blog.

After enduring months of stressful and time-consuming treatments, Brett is now able to have about two ounces of a special powdered milk drink without having an allergic reaction. "Other small studies have achieved similar results, but the children very frequently had reactions, including anaphylaxis," said Dr. Dale Umetsu, who is conducting this research trial along with Dr. Lynda Schneider.

Before trying each taste of even tiny amounts of the milk drink, Brett received painful injections of omalizumab (Xolair®), a medication

that has been used for hard-to-control allergic asthma and is now being tested for its ability to neutralize IgE in the blood of people with food allergy, to make them less sensitive to their allergens. The next step for Brett is a "double-blind" challenge, in which he will not know whether he is getting actual milk or a non-dairy substitute. The goal is for him to be able to tolerate four ounces of milk.

This is not an experiment to try at home. At each research session, an IV line was inserted and Brett was closely monitored by hospital staff. "I was very scared about what might happen the first time they gave me a drink with some milk powder in it," he said, "but I knew that the doctors were standing by and if I had a reaction they could stop it in a minute."

Finding A Cure

"Brett was diagnosed with 15 food allergies before his first birthday," said his mother Robyn Nasuti, a member of the Board of Directors of AAFA New England. "An added benefit of being part of this study is that Brett's asthma has improved a lot," she said, "and I'm hopeful that he is part of finding a cure so that someday my younger son will be able to live his life without food allergies."

If this protocol is shown to be safe and effective, "theoretically we might be able to extend this treatment to almost any other food allergy," said Umetsu, who could not predict when it might become available for other non-study patients. Children's Hospital Boston is looking for other children with milk allergy to participate in this study. For information, contact Irene Borrás at 617-355-6127 or Irene.borras@childrens.harvard.edu.

Complementary and Alternative Medicine: Joining the Mainstream or Still Too Risky?

Recognizing the growing use of various forms of complementary and alternative medicine (CAM), the Journal of Allergy and Clinical Immunology recently published a series of articles reviewing what is known about CAM and its relationship to some areas of allergy and immunology, and highlighting promising research that may lead to new asthma and food allergy treatments.

This may be the first time a peer-reviewed medical journal has published a themed issue about the benefits and limitations of CAM. It provides a wealth of information for physicians, and offers a good opportunity for you to have an important discussion with your allergist to help evaluate the various health modalities you may be using or considering.

The journal issue includes articles that summarize research studies on specific herbs and vitamins and what has been learned about how they work in the human immune system, and offers effectiveness ratings for selected "natural medicines." (For example, choline, magnesium and fish oil are "possibly effective" for asthma, but there is "insufficient evidence" for Vitamin C.) Importantly, there are tables identifying some natural remedies that can cause or exacerbate certain allergic conditions (such as saffron, senna, or sweet cherry), as well as those with the potential to cause interactions with some conventional medicines.

Herbal treatments being tested

Research at the Mount Sinai Medical Center in New York has been particularly productive in the study and development of CAM. Using carefully standardized preparations derived from traditional Chinese medicine (TCM), they have found that many have active effects on the immune system. In particular, one preparation appeared to benefit airway inflammation in animal experiments, and was later tested on 26 patients who use inhaled steroids for asthma. Markers of inflammation in their lungs were distinctly lower than in 25 similar patients who did not use the TCM. This is just one of many studies evaluating Chinese herbal remedies for asthma.

More exciting, perhaps, is the research using these types of treatments for food allergies. Studies at Mount Sinai have shown a remarkable ability of an herbal formula to prevent anaphylaxis in peanut-sensitized mice. The immune systems of the mice that received the 7-herb mixture daily for five weeks were actually altered. As long as 36 weeks after they stopped receiving the herbal formula, 60% of the treated group was completely protected and the remainder had much less severe

anaphylaxis than those in the control group when they were challenged. The exciting aspect of these reports is that the herbal formula has received FDA approval for human use. Preliminary studies have documented its safety, and clinical effectiveness studies have begun. If similar effects as those observed in mice occur in the human studies, a whole new and important treatment possibility would become available!

SOURCE: Journal of Allergy and Clinical Immunology (123:2009)

Frank J. Twarog, M.D., Ph.D., is an allergist in Brookline and Concord, MA, and serves as President of the Asthma and Allergy Foundation of America, New England Chapter. He is a Clinical Professor at Harvard Medical School

What is CAM?

Complementary and alternative medicine can be categorized into whole medical systems, such as homeopathy or traditional Chinese medicine, and four other specific domains: manipulation treatments, such as chiropractic; mind-body medicine, such as biofeedback, meditation or yoga; biologically based therapies, such as herbs, vitamins, or folk medicines; and energy therapies, such as use of electromagnetic fields.

CAM is, obviously, not a new concept. In some countries, it has achieved the status of primary treatment for medical illness. In Western medicine, some of our commonly used medications have, in fact, developed from traditional herbal remedies. These include digitalis and Taxol. Ma huang (ephedrine) has been used in Chinese medicine for over 5,000 years to treat respiratory diseases. Cromolyn, a medication used for treating allergic disease, is a derivative of a grass called khellin used in the Middle East and India for many years to treat respiratory symptoms. Butterbur root has been used in England to treat rhinitis and seems to be comparable to some of our newer non-sedating antihistamines.

Western-trained and -educated physicians may be reluctant to consider using CAM because they have been trained to rely on "evidence-based medicine" as the basis for treatment strategies. Most studies published on CAM are poorly controlled, and there are no quality or safety control data for herbal or other remedies, which have been found to contain heavy metals, mercury, arsenic, and other toxic agents.

More well-designed research is needed to establish reliable information about the safety and efficacy of CAM for people with asthma and allergies. In the meantime, have an open discussion and form a partnership with your physician so that you may explore alternatives safely. More information is available from the National Center for Complementary and Alternative Medicine: <http://nccam.nih.gov>. FJT

GROWING UP WITH ASTHMA OR SEVERE ALLERGIES

How do teens from around New England handle social and school situations involving their asthma and allergies? How do they advocate for themselves, maintain sound treatment plans, or deal with social pressures? Over two hundred high school seniors responded to these questions as part of AAFA New England's annual scholarship competition.

Scholarships of \$1,000 each were awarded to Kristine Tom of Bedford, MA and Timothy Larew of Ellington, CT. Twenty-eight outstanding students were awarded Honorable Mention. These inspiring teens were selected based on their excellent academic records; an amazing array of

activities and community service commitments; and compelling essays on "Overcoming Obstacles to Managing Asthma or Severe Allergies as



a Teen." A booklet of the winning essays is available, on request, from AAFA New England.

While making bird feeders in preschool, **Kristine Tom** accidentally rubbed some peanut butter into her eyes. They immediately swelled up and her throat constricted. She had just discovered she had a severe peanut allergy. By the time she entered kindergarten Kristine had learned how to identify dairy ingredients on food labels, and to avoid the many other foods that could cause severe reactions.

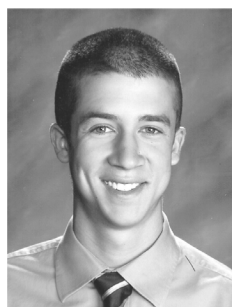
Having multiple food allergies has admittedly been "extremely taxing" for Kristine, who felt left out when she couldn't eat the birthday party cupcakes or candy her teachers gave out as rewards. Kristine has stocked her friends' houses with "safe" foods, and brings snacks everywhere. At restaurants she's careful to ask about ingredients, and if she encounters wait

staff that don't seem to understand the severity of her food allergies she asks to speak to the manager.

When Kristine was a child, asthma attacks could be easily triggered by her friends' pets during sleepovers, and remembers "always having a nebulizer nearby" when she caught a cold. She studied flute, which she believes helped to increase her lung capacity, and found she was able to join her school's field hockey and lacrosse teams.

Kristine says that having asthma and severe allergies has taught her to be more responsible for herself, to be more aware of others' disabilities, and to be assertive, not only when it comes to her health, but in academics and extracurricular activities. This is evident in her success as a varsity lacrosse player, marching band drum major, Class Treasurer, and winner of science competitions.

Timothy Larew's allergies include milk, eggs, peanuts, tree nuts, soy, sesame, and shrimp. He also has asthma, which he knows puts him at higher risk for a severe reaction. Timothy says that living with food



allergies "in a world so focused on food hasn't been easy," but "I can say with absolute confidence that I have never allowed my allergies to stop me from doing anything I've wanted to do."

Timothy credits his mother with helping him to not miss out on opportunities or social activities by teaching him "make sure he had a plan" to handle situations that might arise. At age 7 he wanted to attend a summer basketball camp, so his mother helped educate the staff about food allergies, and arranged to provide campers with wipes to clean their hands after lunch. He became a counselor at that camp, and enjoys working with children who have special needs.

Timothy excels not only at educating others and advocating for himself regarding food allergy safety, but also at academics and athletics. He made High Honor Roll, served as National Honor Society Treasurer and varsity tennis captain.

Both Kristine and Timothy always carry auto-injectable epinephrine in case of an anaphylactic reaction, and have taught their close friends how to use it in case they cannot.

Congratulations to the following students who were awarded HONORABLE MENTION

Nicholas Allred, Sandy Hook, CT
Ashley Alves, Dartmouth, MA
Christine Beecher, Scarborough, ME
Declan "Dan" Bell, Saundertown, RI
Vincent Bennett II, Hollis, NH
Dan Bishop, Wheelock, VT
Hannah Black, Hingham, MA
Carly Boucher, Portsmouth, RI
Kyra Burnett, Wilbraham, MA
Robert Cabral, Raynham, MA
Erica DePinto, Salem, NH
Jessica DeSimone, Lincoln, RI
Tyler DeStefano, Milford, CT
Melanie Donnelly, North Kingstown, RI
Alison Fessler, Andover, MA
Emily Flemming, Gales Ferry, CT
Ilana Freedman, Auburn, ME
Kelsey Karys, Newton, MA
Mwende Katwiwa, Amherst, MA
Joshua Keane, North Attleboro, MA
Jonathan McCurdy, Milton, MA
Kyle Morris, Walpole, MA
Jeremy Novick, Taunton, MA
Matthew Sooknah, Bristol, RI
Jonathan Vignaly, West Boylston, MA
Caroline Vogel, Raynham, MA
Laurel Weatherby, Hampton, NH
Aden Weisel, Avon, CT

Winners were selected by a group of dedicated volunteers who carefully read and evaluated the applications. Thanks to Scholarship Committee members Michele Carrick, Kathleen Dwyer, Deborah Elbaum, Aimee Kaplan, Laifong Lee, Janet Lilienthal, Betsy Luchars, Judi McAuliffe, Penny Paquette, Anne Pickett, Marlene Yesley, and Julie Zirlen.

BREATH OF SPRING 2009

WINE TASTING & AUCTION

at Ferrari • Maserati of New England
Special Sponsors: Ernie and Kristen Boch



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Breath of Spring Committee

Debbie Saryan; Michele Carrick, co-chair; Janet Lilienthal, co-chair

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Fabulous Auction items included theater and sports tickets and gift certificates for restaurants and salons. For a complete list of auction donors, see our website: www.asthmaandallergies.org. Please patronize these generous businesses.



Many thanks to the volunteers and donors who helped make this benefit a success!

Proceeds from the annual Breath of Spring gala support AAFA New England's educational programs, public awareness, advocacy, and support for research to help people live with allergies and asthma.





Our guests enjoyed the fine wines, lavish hors'doeuvres and desserts, and elegant cars.



SPECIAL THANKS to these generous donors:

- Robert Ruscansky and Gail Fischer - photography
- Lisa and Jim Engelbrecht, Creative Sparks Design - invitation design
- Roche Bros. grocers - beverages



Photos by Robert Ruscansky and Gail Fischer

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David & Cynthia White

We have tried our best to acknowledge everyone. If we inadvertently missed you, please accept our apologies and heartfelt thanks for your generosity.

AAFA New England EDUCATIONAL SUPPORT PROGRAMS

Fall, 2009 – Winter, 2010

All groups meet from 7:00 p.m. to 9:00 p.m. unless otherwise noted.

All programs are free and open to the public.

For further information, call AAFA New England, (781)444-7778.

Check our website for updates and driving directions: www.asthmaandallergies.org

MERRIMACK VALLEY ASTHMA & ALLERGY SUPPORT GROUP **North Andover, MA**

Meets at Atkinson Elementary School,
111 Phillips Brooks Rd., No. Andover,
Sept. 30 "Anaphylaxis:

Understanding and Preventing
Severe Allergic Reactions to Foods,
Medicines, Insect Stings and Latex,"
Speaker: John Saryan, MD

Oct. 21 Parent/School Nurse
Roundtable: discussion of school
issues and policies affecting children
with food allergies; Halloween
policies and preparing for the holiday
season

Nov. 18 "Testing Children for
Allergies," allergist Bryan Stone, MD
Dec. 9 "Baking for People with Food
Allergies," Jill Robbins, Founder
of HomeFree Foods and cookbook
author. Meeting will include a holiday
cookie swap/recipe swap.

Jan. 20 Food Allergy Parent
Roundtable - discussion of child-
rearing issues and epinephrine
administration training

METRO-BOSTON ALLERGY & ASTHMA SUPPORT GROUP **Newton, MA**

Meets at Newton-Wellesley Hospital,
2014 Washington St., Newton

Sept. 15 "Food Allergies and
Anaphylaxis: How to Prevent and
Handle Severe Allergic Reactions,"
allergist Curt Moody, MD

Oct. 13 "Asthma, Swine Flu,
Influenza and You," forum featuring
allergist Daniel Steinberg, MD and
others.

Nov. 17 Roundtable: traveling with
food allergies and asthma (tips and
resources for planning and having a
safe trip or vacation)

Jan. 12 "Nourishing, Enjoyable and
Safe Meals for Families with Food
Allergies"

NASHOBA VALLEY ASTHMA & ALLERGY EDUCATIONAL SUPPORT GROUP

Ayer, MA

Meets at Nashoba Valley Medical
Center, 200 Groton Road, Ayer, MA
Sept. 21 "Food Allergies at School:
How to Work with Your Child's
School Nurse to Develop an
Individual Health Care Plan" (panel of
school nurse leaders)

Oct. 26 "Choosing Foods and
Planning Menus for Families with
Food Allergies," Rebekah Donelan
and Susan Morris, registered dietitians

Nov. 30 "Food Allergies: Ask the
Allergist" Bring your questions for
Jordan Scott, MD

NORTHWEST SUBURBAN BOSTON AREA SUPPORT GROUP

Lexington, MA

Meets at Beth Israel and Children's
Hospital Medical Care Center, 482
Bedford St., Lexington, MA.
Directions: Rt. 128, take exit 31B
("Bedford, Rts. 4 & 225"). Get in right
lane to make "Jug handle" U-turn,
then turn into parking lot.

Sept. 14 "Legal Rights of Students
with Asthma and Food Allergies" –
attorney Tim Sindelar

Oct. 19 "Anaphylaxis –
Understanding and Preventing
Severe Allergic Reactions to Foods,
Medicines, Insect Stings, and Latex,"
allergist John Saryan, MD

Nov. 9 "What You and Your Child
Should Know about Asthma" - June
Mayo, RN & Anne Russell, RN

Dec. 14 Roundtable discussion
and recipe swap: "Celebrating the
Holidays with Food Allergies"

Jan. 11 "Ask the Allergist," Bring
your questions for Anahita Dioun, MD

SOUTHEASTERN MASS. FOOD ALLERGY PARENT SUPPORT GROUP **Foxboro, MA**

Meets at Pediatric Specialists, 132
Central St., Suite 116, Foxboro (Exit

7B off Rt. 95 -Route 140 North)
Dates and topics to be confirmed.

FOOD ALLERGY GROUP OF THE NORTH SHORE **Salem, MA**

Meets at Salem Hospital, Davenport
Conference Rooms - First floor
Dates and topics to be confirmed.

METRO-WEST ALLERGY & ASTHMA SUPPORT GROUP **Framingham, MA**

Meets at Allergy & Asthma Treatment
Specialists, 475 Franklin St., Suite
206, Framingham (near intersection of
Mt. Wayte Ave.)

Dates and topics to be confirmed.

SHORESIDE ASTHMA & ALLERGY EDUCATIONAL SUPPORT GROUP

Pembroke, MA

Meets at North Pembroke Elementary
School, 72 Pilgrim Rd.
Dates and topics to be confirmed.

PIONEER VALLEY FOOD ALLERGY SUPPORT **Ludlow, MA**

Meets at St. John the Baptist Pastoral
Center, 201 Hubbard St., Ludlow, MA
Meetings are generally held on the last
Wednesday of the month. Dates and
topics to be confirmed.

CAPE COD ASTHMA & ALLERGY GROUP **Yarmouth Port, MA**

Meets at Allergy & Asthma Center
for Cape Cod, 244 Willow St.,
Yarmouth Port, MA
Call 508-362-0099 for dates and
topics.

RHODE ISLAND ALLERGY & ASTHMA EDUCATIONAL SUPPORT GROUP **Providence, RI**

Meets at Asthma & Allergy Physicians
of Rhode Island, 1056 Hope St.,
Providence, RI
Dates and topics to be confirmed.

Confronting Asthma Together

AAFA New England represents the needs and concerns of asthma patients on state and local coalitions, and provides education and resources so community organizations and health care providers can help you breathe easier.



Mary Zentis, an elementary school nurse in Framingham, Massachusetts, used spacers and educational materials donated by AAFA New England to teach students how to use their inhalers properly and take control of their asthma.

Sharon Schumack, AAFA New England Director of Education, (top row, third from left) brought asthma management tools to a recent meeting of the Greater Brockton Asthma Coalition. The donated spacers, nebulizer kits, and other materials will be distributed by health care providers to low-income patients.



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a year by the

**Asthma and Allergy Foundation
of America**
New England Chapter

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President

and Medical/Scientific Advisor

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Executive Director

Sharon Schumack

Director of Education

BULLETIN Editor

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The Thoracic Foundation*

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.

Information contained in this newsletter should not be used as a substitute for responsible professional care to diagnose and treat specific symptoms and illness. Any reference to available products and procedures should not be construed as an endorsement. AAFA New England, including all parties to or associated with this newsletter, will not be held responsible for any action taken by readers as a result of the newsletter. ©2009. All rights reserved. Material may not be reproduced without permission of the publisher.

BECOME A MEMBER OR RENEW YOUR MEMBERSHIP NOW!

Membership in AAFA New England helps you and others with asthma and allergies to enjoy fuller lives.

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**Honor your friends and relatives
by making a donation to
AAFA New England**

**Donations have recently been
received in memory of:**

**Etta Cousin
Michael Tollins
David Weinrich**

To contribute a memorial gift or tribute in honor of a special person or a birthday or other event, please send a check payable to AAFA New England. (MC/VISA accepted by phone or mail.) Please include the name of the person being honored or memorialized, and let us know who to notify of your donation.

FOOD ALLERGY CORNER

"Adopt an Allergen" Food Allergy Awareness Idea for Elementary Schools

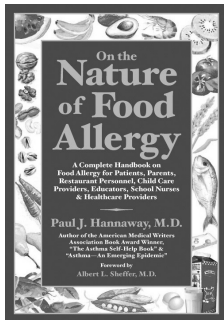
Amédée B. Maggard, founder of a Florida food allergy parent group, created this educational exercise to raise awareness about food allergies. It teaches all children about reading food labels and cross-contamination, and heightens their sense of empathy towards fellow students who may have food allergies. *Here's how it works:* Each elementary age student "adopts" one of the top eight allergens (milk, eggs, peanuts, tree nuts, fish, shellfish, soy, wheat). The student has to avoid the selected allergen for one week. The students' families will become involved in helping to identify ingredients to ensure that he/she is avoiding the allergen. At the end of the week, teachers, students and parents will discuss their week of avoidance: the lifestyle changes they made and what they learned and experienced.

Managing Food Allergies in Schools: A Training Program

To help schools get ready for a successful year, school nurses and others can use this program, developed by AAFA New England, to teach the entire school community about food allergies. It includes an overview of food allergies and anaphylaxis; decreasing exposures to particular foods in classrooms, cafeteria, on field trips, etc.; and how to plan for an emergency. Makes a great gift for the school nurse, and helps your child, too! (CD; \$25.00 plus \$2.00 shipping/handling.) Call AAFA NE to order (toll free: 877-227-8462).

FREE!

Everything You Ever Wanted to Know about Food Allergy



On the Nature of Food Allergy is a comprehensive and delightfully written handbook about all aspects of food allergy by the late Dr. Paul Hannaway, an esteemed Boston-area allergist and dedicated AAFA New England Board member. Thanks to a generous donation from the Hannaway family, we are offering a free copy of this fabulous resource to members who join or renew this fall. It is a \$20.00 value and supplies are limited. To join or renew, see page 7, call the office (toll free: 877-227-8462), or visit www.asthmaandallergies.org.

Marathon Runner Keeps Family Members and AAFA New England in Mind

When Susan Kennish's brother Michael Tollins died tragically of asthma in 2005 at the age of 35, she made a commitment to keep his memory alive and raise awareness about the illness that took his life. She has followed through with great success by



completing the 2009 Nashville Country Music Marathon as a charity event to benefit AAFA New England.

Congratulations to Susan, and our sincere appreciation to her supporters. Sadly,

Susan and Michael's grandmother, Etta Cousin, also died recently and many generous donations were made in her memory. AAFA New England will work hard to honor their memory by helping others with asthma to live longer and healthier lives.

Please call us if we can help to honor or memorialize your loved one when you participate in races or celebrations, have milestones (birthdays, anniversaries), or just want to honor someone special.



Asthma and Allergy
Foundation of America®

NEW ENGLAND CHAPTER

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To receive future issues at home, become a member of AAFA New England. (See page 7)*