Asthma is a chronic disease of the small airways in the lungs. Uncontrolled asthma symptoms can make breathing difficult and interfere with active, healthy lives. While there is no cure, it can be managed and controlled. "When appropriately managed through medications, trigger avoidance, and monitoring, most patients with asthma can lead active, healthy lives. AAFA New England helps patients attain this goal through advocacy and education." Elizabeth TePas, M.D., M.S., AAFA New England Board Member

ASTHMA FACTS in Massachusetts
- The prevalence of asthma is higher in Massachusetts than in any other state in the United States.
- 41% of children with asthma miss school or daycare at least one day per year due to their asthma.
- Springfield, MA has the highest rate of reported asthma than in any other city in the country.

COMMON SYMPTOMS OF ASTHMA
Coughing, Shortness of Breath, Wheezing, Chest Tightness.
Dear Readers,

It is Spring in New England with the promise of warmer days, new growth and, once again, peak season for people with asthma and allergies. May is “National Asthma and Allergy Awareness Month.” For the Asthma and Allergy Foundation of America, New England Chapter (AAFA New England), it is peak season to connect with people who cope with the effects of asthma and allergies. It is a perfect time to re-dedicate our Spring 2019 Bulletin to provide timely information, education and support to families, friends, and patients about these diseases.

During Asthma and Allergy Awareness Month, we hope you will participate by raising your own awareness of the multiple dimensions of allergy and asthma, and encouraging others to increase their knowledge of the issues.

• Go to the AAFA New England website (asthmaandallergies.org) and expand your knowledge and awareness of asthma and allergy conditions and what to do about them. Do you know someone who has asthma or allergies? Show them that you care. Point them to AAFA New England’s website and our online resources and events.

• Like us on Facebook or follow us on Twitter and post something that you’d like to share with the asthma and allergy community. It is through our community that we show support for others and, in turn, remind ourselves that we are not alone. By sharing, we grow our community.

• Plan a special day or event at home, work or school that highlights allergies and asthma and helps spread awareness.

• See page 5 for reports on Asthma Capitals™ and Allergy Capitals™.

"Understanding Sesame Allergy” focuses on sesame allergies, the need for effective labeling, and offers a primer on what we need to know. “All About Asthma” was developed specifically for this issue of our Bulletin to offer important facts about asthma, symptoms, triggers, management tools and control.

AAFA New England is involved in advocacy for public policies that can make a difference. A sampling of our activities appears on page 3.

We are announcing SAGE (Support – Advocacy – Group Education) and our plans to develop a number of support groups that will be launched in the fall. See page 4 and get involved!

Our Speaker Series events book-end Asthma and Allergy Awareness Month. We hope you will take advantage of these informative talks throughout the year by experts in their fields. Join us in person, watch LIVE online or view the talks which we now post on our website.

During Asthma and Allergy Awareness Month, we invite you to show your support of AAFA New England and our work as the only organization in New England that is devoted to both asthma and allergies. Your financial support drives our ability to extend our reach throughout all the New England states. You can make a difference!

Warm regards,

David Guydan
Executive Director
ALL ABOUT ASTHMA (continued from page 1)

COMMOM TRIGGERS OF ASTHMA
A trigger is something that can make your airways inflamed causing symptoms of your asthma. They can include:
- Tobacco smoke, including secondhand smoke
- Outdoor air pollution
- Infections and colds
- Pollen
- Mold
- Dust mites
- Pets (e.g., dogs, cats)
- Rodents, including mice
- Chemicals
- Exercise
- Stress
- Extreme changes in weather

ASTHMA MANAGEMENT TOOLS
- **Asthma Action Plan:** A form that has information and instructions to follow which will help you manage your asthma. It can be used at home and at school. Know your “asthma zones”: Green = Safe; Yellow = Caution; Red = Emergency. Peak flow meters are used for home lung function monitoring by some asthma specialists.
- **Inhaler:** A device used to deliver inhaled asthma medicine.
- **Spacer or Holding Chamber:** A device that attaches to some inhalers in order to help more asthma medicine reach your lungs.
- **Nebulizer:** A machine with tubing that takes liquid asthma medicine and delivers it as a mist for you to inhale.

ASTHMA MEDICATIONS
- **Quick-relief medications:** Bronchodilators (e.g., albuterol)
- **Long-term controller medications:** Inhaled steroids, alone, or in combination with a long-acting bronchodilator, for example
- **Therapies for more severe asthma:** Oral steroids, long-acting muscarinic antagonists, biologic agents, bronchial thermoplasty

ASTHMA MANAGEMENT AND CONTROL
Good asthma management requires five components:
1. Evaluation, treatment and regular follow-up care with your healthcare provider, such as your allergist, pulmonologist, or primary care clinician.
3. Talking with your healthcare provider to make sure you understand how to use your inhaler and spacer correctly and understand the difference between the two types of asthma medicines (long-term controllers and quick-relievers).
4. Knowing your triggers, controlling environmental triggers, and avoiding them whenever possible.
5. Using your asthma medications as prescribed by your asthma specialist.

“As someone with childhood asthma, I remember not being able to breathe and sitting on the sidelines during sports. Thankfully, my Allergist identified my asthma triggers and prescribed medications so I no longer had to worry about whether I could breathe. Now, as a Pediatric Allergist, I strive to help all of my patients with asthma live without limits. AAFA New England provides excellent resources to help patients and families achieve this goal.”  
Lisa Bartnikas, M.D., AAFA New England Board Member

For more information about AAFA New England’s programming and resources to help you manage asthma, please go to our website: asthmaalldergeries.org, or call us at 781-444-7778.

LEGISLATIVE ADVOCACY
In New Hampshire, AAFA New England Board Member, Bob Stoker, testified before the Senate Committee seeking to establish a permanent committee to study the needs of rare disease patients, a group that includes certain asthma phenotypes and patients with forms of allergic urticaria.

At the Massachusetts State House on May 2, 2019, Dr. Michael Pistiner, Board President Jan Hanson and Laurel Francoeur, made presentations at a briefing hosted by Senator Cynthia Creem to learn more about and discuss S.255, An Act to Establish Food Allergy Plans in schools.

AAFA New England is advocating to pass S.1226, An Act to Improve Food Allergy Awareness, as it relates to food preparation and food service in MA restaurants. In Connecticut, we are working with parents whose children are affected by food allergies to gain traction on new public policies relating to how restaurants handle patrons with food allergies.

We Work for Health Partner Fly-in
On April 10-11, 2019, David Guydan, AAFA New England Executive Director, joined a delegation of people from 12 states in DC to meet with our respective representatives on Capitol Hill, advocating for a Health and Human Services proposed rebate rule that would lower out-of-pocket costs at point-of-sale for Medicare Part D beneficiaries. Our MA delegation met with representatives of Senator Ed Markey and Representatives Ayanna Pressley, Katherine Clark and Richard Neal.

UNDERSTANDING SESAME ALLERGY (continued from page 1)

This lack of transparent labeling may significantly limit safe food options and potentially result in life threatening reactions. As sesame allergy has substantial impact, many food allergy advocates support inclusion of sesame as a major food allergen that is included under the FALCPA.

In 2018 the FDA, after petitions from medical experts and advocacy groups, opened a request for information (RFI) in consideration of including sesame under the FALCPA. The request for information was open until December 31, 2018. FDA is currently reviewing submissions and comments and considering including sesame as a major allergen.

If you are experiencing reactions to foods that you suspect may contain sesame, do not continue eating those foods. You should seek treatment immediately, alert your medical care provider, and retain packaging from the food or beverage product.
**AAFA New England: NEWS AND NOTES**

**Massachusetts Researcher Day Breakfast, March 5, 2019**

AAFA New England was invited by The Strategy Group to meet for breakfast and an inspirational talk by Carl Scortino, VP of Government and Community Relations at Fenway Health. Afterwards, researchers from bio-pharma companies across the state met with MA State Legislators to share their experiences and discuss their work in finding cures for diseases.

**New England Society of Allergy (NESA) Spring Meeting, March 29, 2019 Westford Regency Conference Center**

Board Member Bob Stoker and David Guydan attended as exhibitors at the NESA Spring Meeting. Lisa Bartnikas, MD, Board Member and Medical Advisory Committee Member, moderated the program which offered CME and CEU accredited presentations for NESA members and their nursing and support staffs. The Meeting was well attended by sponsors representing pharmaceutical companies and others in the field.

**AAFA/LG Electronics USA Partnership Kicked Off Asthma and Allergy Awareness Month**

AAFA New England helped to identify a family in Springfield, MA (#1 Asthma Capital and #5 Allergy Capital) with a suite of asthma and allergy friendly™ products. AAFA New England, through David Roberson, MD, a board-certified allergist and immunologist in Springfield, identified a family of asthma and allergy sufferers who received air purifiers, laundry equipment and other products to alleviate the stress of asthma and seasonal allergies in their home.

**Be Smart and Breathe Easy**

As a result of AAFA New England’s 2018 Be Smart and Breathe Easy Asthma Program conducted in three inner-city Boston schools, original resource documents were created to help schools manage their students affected by this chronic condition. These resources, written in both English and Spanish, address both disease management and asthma environmental trigger remediation. It is our goal that these resource documents will further our reach to help improve the quality of life for students with the diagnosis of asthma.

These free materials are posted on our website, asthmaneadlergies.org.

**AAFA New England Announces New (and Re-Newed!) Support Groups**

It has long been recognized that living with asthma and allergies often creates feelings of anxiety for families and generates identity and isolation issues in children. Patients and their families receive top-notch medical and psychological care throughout our region but, outside the medical facilities, living with asthma and allergies can be daunting. Today’s access to the Internet fills a need for information but that information is not always accurate, and the internet cannot help families cope with the emotional aspects of managing these conditions. Many families express a desire to create opportunities to meet with others who are experiencing similar issues. That is why AAFA New England created SAGE. Groups will be forming over the summer with launch dates this fall.

What is SAGE?

- Physician-advised, community-based groups that offer support and share information, tips and products
- Clearinghouse for fact-based information, education and speakers on topics of interest
- Opportunities for advocacy at the local, state and national levels

Where are initial SAGE locations planned?

- Massachusetts, New Hampshire, Rhode Island, Connecticut and Maine

How to start or find a SAGE near you?

- Contact us at aafa@aafane.org or call 781-444-7778.
- Express your desire to be a SAGE member and help drive the agenda for your local SAGE.

We believe that information is empowering and support is transforming. Join us in helping one another improve the lives of people throughout our six-state region who are impacted by the effects of asthma and allergies through SAGE.

**Past Event – Flying with Food Allergies: Planning Summer Travel**

On April 24th, AAFA New England’s 2019 Speaker Series kicked-off with Attorney Laurel Francoeur’s well-received presentation addressing the unique circumstances for people flying with food allergies from picking an airline to choosing meals and snacks onboard, as well as passenger legal rights. Laurel shared tips on how to fly safely and how allergic reactions are handled in the air. Judging from the questions and the sharing of stories, Laurel’s talk struck a responsive chord! JetBlue supported the event with allergy-friendly snacks and information about JetBlue protocols for passengers with food allergies who self-identify.
On World Asthma Day, May 7, 2019, the Asthma and Allergy Foundation of America (AAFA) released its 2019 Asthma Capitals™ report, which lists the 100 most challenging places to live with asthma in the U.S. Cities are ranked based on asthma-related health outcomes: prevalence, emergency room visits and mortality, as well as risk factors that contribute to these outcomes: poverty, air quality, access to specialists, pollen counts, medicine use, tobacco policies and the rate of uninsured residents. Last year’s asthma capital, Springfield, MA, is again the most challenging place in the U.S. to live with asthma. Politicians and community leaders in Springfield are intent on improving conditions in Springfield. Senator Eric Lesser of MA shared examples of what is being done to improve conditions in Springfield:

- Preventing a new biomass plant from coming to Springfield
- Better public transportation to take cars off the roads
- Promoting electric vehicles through rebates
- Creating incentives for home energy efficiency

The Asthma Capitals™ ranking, we hope, raises awareness about the impact of asthma and highlights how communities can make improvements to serve their residents with asthma better.

From the Top 100 Asthma Capitals™, we have selected the locations in New England that ranked highest:

1. Springfield, MA (also #5 on Allergy Capitals™)
2. Providence, RI
3. Springfield (also #1 on Asthma Capitals™)
4. Hartford, CT
5. New Haven, CT
6. Worcester, MA
7. Bridgeport, CT
8. Boston
9. New Haven, CT
10. Hartford, CT

To see the full list, visit asthmacapitals.com

On March 12, 2019, the Asthma and Allergy Foundation of America (AAFA) released its yearly Spring Allergy Capitals™ report. The report looks at three important factors:

- pollen and mold count
- allergy medicine use
- availability of board-certified allergists

The locations high on the listing are there due to higher than average pollen and medicine use and lower than average availability of board-certified allergists.

More than 50 million Americans with seasonal nasal allergies are expecting – and dreading – runny and congested noses, inflamed sinuses, relentless sneezing and other symptoms associated with springtime allergies. As warmer weather sends people outdoors to face one of the season’s biggest problems, tree pollen, children and adults should plan ahead.

We hope this report helps our readers to be more aware of their allergy triggers and more prepared to deal with the symptoms.

From the Top 100 Allergy Capitals™, here are the locations in our AAFA New England six-state region that made the list!

1. Providence, RI
2. Hartford, CT
3. New Haven, CT
4. Bridgeport, CT
5. Boston, MA
6. Worcester, MA
7. Springfield (also #1 on Asthma Capitals™)
8. Springfield (also #5 on Allergy Capitals™)

To see the full list, review study methodology and learn more about dealing with your allergies, visit: www.allergycapitals.com

In March, 2019, AllergyEats announced its 2019 list of the Top 10 Allergy-Friendly Restaurant Chains in the U.S. Derived from the restaurant reviews of food-allergic diners across the U.S., the list recognizes both small and large restaurant chains that have been ranked highest. Congratulations to these restaurant chains for their dedication to supporting the food allergy community with consistent protocols and workforce education and training.

Top five most allergy-friendly large chains (at least 50 locations)

- Maggiano’s Little Italy
- Chipotle Mexican Grill
- Longhorn Steakhouse
- In-N-Out Burger
- Bertucci’s Italian Restaurant

Top five most allergy-friendly small chains (fewer than 50 locations)

- Burton’s Grill
- Flatbread Company
- Clyde’s Restaurant Group
- 110 Grill
- Weber Grill
The Asthma and Immunology Department at Boston Children's Hospital is currently recruiting for several studies in which patients can participate. If you feel that you might qualify and you are interested in taking part in important research in the field, please contact Boston Children's Hospital directly: Felice Chan 617-355-4349.

**Atopic Dermatitis**

We are currently looking for patients who have severe Atopic Dermatitis (AD) to participate in one of two investigational drug trials at Boston Children's Hospital.

In one study, children may be eligible if they:
- are between 6 months to 5 years of age.
- have been diagnosed with Atopic Dermatitis.
- have had Atopic Dermatitis for at least 6 months.

In another study, children may be eligible if they:
- are between 12 years to less than 18 years of age.
- have been diagnosed with Atopic Dermatitis.
- have had Atopic Dermatitis for at least 1 year.

**Peanut Allergy Study for Ages 1-3**

The EPITOPS Study Team at Boston Children's Hospital is conducting a study to look at the safety and efficacy of the Viaskin® Peanut patch in children. This patch tries to make children less sensitive to peanuts by continuously delivering small amounts of peanut protein through the skin.

Who may be eligible?
- Children 1-3 years old
- Physician diagnosed peanut allergy with documentation in the child's medical records

What is involved?
- 12 visits over the course of 12 months at Boston Children's Hospital
- Peanut food challenges at the beginning and at the end of the study
- Skin prick testing and blood draws 4 times during the study

Compensation will be provided at the study visits. For more information contact: EPITOPE Study Team at Foodallergystudies@childrens.harvard.edu or call 617-355-4301.

HARTFORD YARD GOATS

Parents' Concerns Generate Response

The Hartford Yard Goats, a Double-A Eastern Affiliate of the Colorado Rockies Baseball Team, announced earlier this year that for the 2019 season peanuts would no longer be sold at their Dunkin' Donuts Park. The primary motivation to make the park peanut allergy-friendly, according to Tim Restall, President of the Hartford Yard Goats, was to “do the right thing” after talking with concerned parents. AAFA New England salutes Time Restall and the Hartford Yard Goats for making a peanut safe ball park to root for the home team.

Want to attend a peanut allergy-friendly free game? Contact the Hartford Yard Goats at 860-240-5591 or visit www.MiLB.com/hartford.

**Multiple-food oral immunotherapy (OIT) (peanut and 2 other foods) + Omalizumab NCT #03881969**
- Phase III study - Enrolling Summer 2019; Ages 2-55

**Early Peanut Introduction Study NCT# 03019328**
- Observational study; Ages 4-11 month old

**Peanut OIT for Infant/Toddler NCT# pending**
- Phase II study – Enrolling Fall 2019; Ages 6-17 months old

**Peanut OIT + Dupilumab NCT #03682770**
- Phase II study - Enrolling late Spring 2019; Ages 6-17 years old

**Peanut Recombinant DNA Vaccine NCT #03755713**
- Phase I – Enrolling now; Ages 12-17 years old

**Peanut OIT + Probiotic (live biotherapeutic product) NCT# pending**
- Phase Ib/II - Enrolling Spring/Summer 2019; Ages 12-55 years old.
- The study will evaluate pretreatment or concurrent treatment with probiotic in comparison to low-dose peanut OIT alone.

**Observational study; Ages 2-55**

**Phase III study - Enrolling Summer 2019; Omalizumab NCT #03881969**
- Multiple-food oral immunotherapy (OIT) (peanut and 2 other foods) + Omalizumab NCT #03881969
- Phase III study - Enrolling Summer 2019; Ages 2-55

**Fall Gala 2019**

Join us as we celebrate AAFA New England’s 40th Anniversary and honor three Champions of the Asthma and Allergy Community:
- Kyle Dine, internationally known singer/songwriter who educates children about food allergies through song
- Dr. Chris Fanta, Director of the Partners Asthma Center and Professor, Harvard Medical School
- Mark and Gail Elvidge, Vermont Nut Free Chocolates, founded in 1998
AAFA New England is grateful for the support of our Corporate Partners in 2019. Their generous support allows us to provide valuable resources to help our members live life fully with asthma and allergies.

The Thoracic Foundation

BECOME A MEMBER OR RENEW YOUR MEMBERSHIP!

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

- Individual $35
- Family (2+) $50
- Professional (MD & RN) $100
- Practice Group $250

MEMBERSHIP INCLUDES

- Newsletters mailed to you (Multiple copies to Professional members)
- Personalized resources and information
- Notice of educational programs and special events

Dues can be paid via check made payable to: AAFA New England or credit card on our website www.asthmaandallergies.org

MAKE A DONATION TO AAFA NEW ENGLAND

Donations are gratefully accepted via check made payable to:
AAFA New England or credit card on our website www.asthmaandallergies.org

- $50
- $100
- $175
- $250
- $500
- $___________ another amount

Honor your friends and relatives by making a donation to AAFA New England. Please include the name of the person being honored or memorialized, and whom you want us to notify of your donation. All donations are tax-deductible.

Please remember to ask your company for a matching contribution to AAFA New England.
AAFA New England ANNOUNCEMENTS

Family Concert and Food Allergy Expo
October 26, 2019, 2:30 to 4p.m. Venue to be announced

Kyle Dine is a performer and educator who writes and performs songs that empower, support and educate children with food allergies, their parents and friends. All are welcome to dress up in Halloween costumes to add to the fun.

Jyotsna Mehta
Founder, Keva Health
“Digital Health and Patient Engagement” moderated panel discussion and webinar Wednesday, June 19, 2019 7:00 - 8:00 p.m.
AAFA New England Office
25 Braintree Hill Office Park Suite 200, Braintree, MA

SAVE THE DATE!
MSIC Golf Tournament
Monday, August 26, 2019
Join us at Black Rock Country Club, All proceeds benefit AAFA New England.

To register for the Speaker Series, call AAFA New England at 781-444-7778, email us at events@aafane.org, or visit our website.

Beth Klements
MS, PPCNP-BC, AE-C
Boston Children's Hospital, Asthma Clinical Nurse
“Asthma Basics: When to Pay Close Attention; When to Start to Worry” Tuesday, May 28, 2019 6:30 - 7:30 p.m.
Boston Children's at Waltham Deverber Room
9 Hope Ave., Waltham, MA