# Asthma & Allergy Bulletin

ASTHMA AND ALLERGY FOUNDATION OF AMERICA • NEW ENGLAND CHAPTER

# Join Us!



Food Allergy Conference & Expo Sheraton Boston Needham Hotel Saturday, May 31<sup>st</sup> 12:30pm - 5:30pm



Falmouth Road Race Falmouth, MA Sunday, August 17<sup>th</sup> 9:00am



**2025** *for life without limits* ™ Fall Gala and Exhibit UMass Club Boston Friday, October 24<sup>th</sup> 6:00pm - 10:00pm

# Advocacy: A Vital Role in Creating Change

#### By Erin Hearn, Esq.

Advocacy is a powerful tool for driving social change, influencing policy, and raising awareness about critical issues. It involves speaking up, taking action, and championing causes to improve the lives of individuals and communities. Advocacy takes many forms, from grassroots efforts to legislative lobbying, and it empowers people to have a voice in decisions that impact them.

Advocacy is essential because it brings attention to issues that might otherwise go unnoticed. By engaging in advocacy, individuals and organizations can shape policies, secure funding for research and programs, and ensure that underserved populations receive the resources and care they need. Advocacy also fosters community involvement and collaboration, creating a united front to address pressing challenges.



AAFA New England has been a valuable partner in advocating for policies that improve the quality of life for those with asthma and allergies. The AAFA New England community has been actively involved in advocating for cleaner air, equitable healthcare access, and better education about asthma and allergy management. Over the years, we have collaborated with policymakers and other stakeholders to strengthen legislation requiring school personnel training to prevent allergic reactions, allow patients to utilize copay assistance to lower the costs of their medications, and make restaurants safer for persons with allergies.

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# Non-IgE-mediated Food Allergic Conditions Defined

By Qian Yuan, MD, PhD

Non-IgE-mediated food allergic conditions usually occur early in childhood. These conditions include Food Protein Induced Allergic Proctocolitis (FPIAP), Food Protein Induced Enterocolitis Syndrome (FPIES), Eosinophilic Esophagitis (EoE), and Eosinophilic Gastrointestinal Disorder (EGID).



#### **FPIAP** (Food Protein Induced Allergic Proctocolitis):

onset of symptoms of mucously bloody stools, GER, feeding difficulty and poor sleep typically occurs between 2 weeks and 2 months of life. The most common triggers are dairy protein and soy protein.

**FPIES** (Food Protein Induced Enterocolitis Syndrome): onset of symptoms usually occurs around 6 months of age with delayed profuse vomiting, pallor and lethargy after ingesting offending food trigger(s). The most common triggers are dairy, oat and rice.

**EoE** (Eosinophilic Esophagitis): there is a bimodal occurrence, between 5-10 years of age in childhood and 20-30 years of age in young adulthood. About 50% of EoE patients have evidence of IgE sensitization to foods.

Children with a history of FPIAP have increased risk of IgE food allergies (5 folds to dairy, 2 folds to egg and 1.4 folds to peanut) and increased risk of EoE by 6 folds. Although there is no direct relationship between FPIAP and FPIES, and FPIES and IgE food allergies or EoE, about half of FPIES children have a history of FPIAP, and about 5-25% of FPIES patients have IgE sensitization to foods (this is called atypical FPIES). There is likely a connection between the non-IgE-mediated food allergic conditions in early infancy and the IgE-mediated food allergies later in life.

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## 2025 AAFA New England Board of Directors

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#### Announcing our Food Allergy Conference & Expo! Get your tickets today!

This afternoon Food Allergy Conference & Expo will be held at the Sheraton Boston Needham Hotel, a location accessible for attendees traveling from around the region. The program will include workshops, an informal "Chat and Connect" and an exhibitor area. Join us for meaningful opportunities to learn from recognized experts, to connect with others in the local food allergy community, and to explore related products and services.

#### **Topics and Speakers**

#### Updated Recommendations for Food Allergy Management Guidelines at School, K-12

Michael Pistiner, MD, MMSc – Director of Food Allergy Advocacy, Education and Prevention, MassGeneral Hospital for Children, Food Allergy Center

Christine Creter – Learning and Performance Strategist Principal and Founder, Creter Group, Inc

#### Anxiety and Food Allergies: Strategies for Patient and Caregiver Wellbeing Through the Ages

Lisa Bartnikas, MD – Attending Physician, Division of Allergy, Boston Children's Hospital / Assistant Professor of Pediatrics, Harvard Medical School

Sara Voorhees, PhD – Attending Psychologist, Immunology Division, Boston Children's Hospital / Instructor of Psychology, Harvard Medical School

Emilé Baker, LICSW – Psychotherapist in Private Practice / Associate Professor of Practice, Simmons University School of Social Work

#### What's New in Food Allergy Treatments

Sarita Patil, MD – Co-Director, Food Allergy Center, MassGeneral Hospital for Children / Assistant Professor of Medicine, Division of Allergy & Immunology, Harvard Medical School

Traveling with Food Allergies: A Guide to Safe and Confident Adventures
Kyle Dine – Founder, AllergyTravels.com / Co-Founder Equal Eats /
Food Allergy Educator. Performer. Musician. Puppeteer. Speaker

#### **Conference Tickets \$45**

Scan the QR code or visit asthmaandallergies.org to purchase

Interested in exhibiting or sponsoring the Conference? Contact us at events@aafane.org

### Highlights from AAFA New England's 2024 for life without limits ™ Fall Gala and Exhibit

Our 2024 Fall Gala and Exhibit was an informative, impactful and inspiring evening!

Board members, champions, supporters, sponsors, friends, & family celebrated AAFA New England's 45th year!

**Gaurab Basu, MD, MPH** delivered an educational and hopeful keynote address, "Climate Change and its Impact on the Health of Individuals Managing Asthma and Allergies."

Our 2024 Champions of the Asthma and Allergy Community: **Aleena Banerji, MD, Cindy Guo, CPhT and Hans Oettgen, MD, PhD** were recognized for their outstanding work in the field of asthma and allergies.

We are thankful for the support of our community! As we begin the next 45 years, our work to improve the quality of life for those living with or caring for someone with asthma, allergies and related diseases continues throughout New England!



2025 Fall Gala and Exhibit for life without limits™

Join us for our 2025 Fall Gala and Exhibit! Exhibits and sponsorships are available at asthmaandallergies.org

### Advocacy: A Vital Role in Creating Change (continued from page 1)

There are many ways individuals and families affected by asthma and allergies can participate in advocacy. You can join AAFA New England's advocacy network to stay informed about legislative issues and participate in campaigns throughout New England. Writing letters or emails to elected officials, signing petitions, and sharing your personal story with decision-makers are powerful ways to make your voice heard. You can also attend public hearings, join rallies, or even meet with policymakers to discuss key issues. Advocacy can be as simple as having a conversation with your neighbors about the issues that are important to you. Building awareness is an important element of successful advocacy! We work with our network of stakeholders and policymakers to ensure you have the information and tools you need to tackle these critical issues.

Advocacy is a shared responsibility that allows us to create meaningful change. By taking action, we can work together to build a future where everyone with asthma and allergies can breathe easier and live healthier lives. Join us in making a difference—your voice matters! Interested in AAFA New England's Advocacy Network? Contact us at aafane@aafane.org



Erin Hearn, Esq. is the Senior Vice President of Alliance Development at J Strategies Inc. J Strategies takes an innovative approach to advocacy, combining traditional, digital, and emerging media strategies with ally development and government affairs.

## Non-IgE-mediated Food Allergic Conditions Defined (continued from page 1)

Dysbiosis of the gut microbiome has been shown to play a role in developing FPIAP and FPIES. Better understanding the factors which lead to the dysbiosis in early infancy will not only help understanding the disease mechanisms of FPIAP and FPIES, but also facilitate better management to correct the dysbiosis and treat FPIAP and FPIES.

It is conceivable that the Atopic March likely starts with the non-IgE-mediated food allergic conditions, particularly FPIAP, in early infancy, and lead to eczema, IgE-mediated food allergies, asthma, allergic rhinitis, and EoE.

Recognition of the non-IgE-mediated food allergies and management of these conditions will likely affect the development of IgE-mediated food allergies. Current clinical practice guideline of diet avoidance until 1 year old for managing FPIAP is subject to further discussion. Lack of antigen exposure in early infancy or delayed introduction of high allergic foods in infancy are known to increase the risk of IgE-mediated food allergies.

Maintaining efficient allergen exposure and modulate infant gut immune response via prebiotics or probiotics will likely alter the immune/allergic response, and likely alter the progress of Atopic March!



Qian Yuan, MD, PhD, Co-Director of the MGH Food Allergy Center and senior clinician in the Division of Pediatric Gastroenterology and Nutrition was appointed the inaugural incumbent of the Demarest Lloyd, Jr. Endowed Chair in Food Allergies in May 2023. Dr. Yuan is an Associate Professor in Pediatrics at the Harvard Medical School. He is dedicated to advocating for his patients through collaboration with other physicians and scientists in pediatric allergy and immunology, child psychology, nutrition, and feeding and swallowing. Dr. Yuan's research interests include food allergic diseases that affect the gastrointestinal tracts of children.

For more information on EoE, check out A Fresh Look at Eosinophilic Esophagitis (EoE) in the Spring by Sarita Patil, MD in the Spring 2023 issue of the Asthma & Allergy Bulletin at asthmaandallergies.org.

## 2025 State Honor Roll™ - Asthma and Allergy Policies for Schools



The 2025 State Honor Roll<sup>TM</sup> - Asthma and Allergy Policies for Schools identifies states with the best public policies for people with asthma, food allergies, anaphylaxis and related allergic diseases in U.S. elementary, middle and high schools. The findings tell us that while some policies are in place for kids with asthma and allergies at school, there's room for improvement.

In New England, Connecticut earned Honor Roll status. Massachusetts and New Hampshire earned Honorable Mention. Rhode Island, Maine and Vermont are close to earning Honorable Mention.

As legislative sessions get underway, AAFA New England will work to support progress on policies that will ensure schools are safe and healthy for children with allergies and asthma. We will provide updates to our community and share ways to get involved.

Learn more at statehonorroll.org

# **AAFA New England: News & Notes**



For the 4<sup>th</sup> consecutive year, Team AAFANE will run in the ASICS Falmouth Road Race! As part of the **Numbers for Nonprofits** program, our runners raise funds and awareness for AAFA New England – supporting the work we do for the asthma and allergy community. Last year, our team of 15 runners raised over \$20,000! Stay tuned for ways to support this year's Team!



AAFA New England President, Jan Hanson and Executive Director, Lori Rohleder joined the AAFA National team – including AAFA CEO and President, Kenneth Mendez - at the American College of Allergy, Asthma & Immunology Conference at the Hynes Convention Center in Boston. ACAAI is a professional medical organization of more than 6,000 allergists, immunologists and allied health professionals.

As part of 31 Nights of Lights, AAFA New England Board members, family and friends 'flipped the switch' to light the Prudential Tower in teal in support of AAFA New England's mission to improve the quality of life for all affected by asthma and allergic diseases throughout our region. The Spring issue of the Asthma & Allergy Bulletin will include details on our plans to light the Prudential Tower in teal to promote Asthma and Allergy Awareness month.





AAFA New England supported the MGH Food Allergy Buddies "Design an Exhibit Experience" program at the Museum of Science, Boston. Buddies Teams created and presented their exhibit ideas to each other, parents and our community. A fun and inspirational day!

# Research Clinical Studies: Opportunities to Get Involved



- IDEA (Investigating Dupliumab's Effect on Asthma by genotype) We are studying if people have a certain genetic make-up (genotype) will respond better to dupliumab. Adolescents and Adults age 12 and above with asthma are eligible. https://answers.childrenshospital.org/duplimab-asthma/ https://ideaasthma.org
- CHEETAH (Mechanisms Underlying Asthma Symptoms and Exacerbations Across T2 status in children. We are studying if there are different mechanisms in asthma symptoms during asthma exacerbations. Children age 6 17 with asthma are eligible.
- **ADRN** (Atopic Dermatitis Research Network) We are investigating mechanisms of atopic dermatitis in any age 2 and above. This study wants to understand how the severity of atopic dermatitis or eczema is influenced by genetic factors.
- LEADS Longitudinal Endotyping of Atopic Dermatitis through Transcriptomic Skin Analysis (Atopic Dermatitis Research Network) We are aiming to learn certain characteristics of the skin and how those characteristics are related to the severity of Atopic Dermatitis and the skin's response to different treatments. Anyone age 6 and above are eligible, including adults. We are also recruiting healthy controls.
- EAGLE (A Randomized, Placebo-Controlled, Double-Blind, Multicenter, Phase 2 Study to Assess the Efficacy and Safety of Daily OM-85 Treatment vs. Placebo given in Children Aged 6 Months to 5 Years with Recurrent Wheezing) We are studying whether babies with wheezing will benefit from an oral treatment that modifies the gut microbiome.
- SICAS-3 (School Inner-City Asthma Study) We are evaluating whether children and adults with or without asthma have novel signatures in asthma control. Children and adults 5 and above including healthy controls are eligible.

Boston Children's Hospital studies provide free treatments, \$\$ compensation for time and travel. For more information about any of the above BCH studies and/or to refer potential interested families, please email:asthma@childrens.harvard.edu OR call 857- 218-5336 OR see website https://bchasthmaresearch.com

Scan to participate



Scan QR code to learn more



# Massachusetts General Hospital

Contact: Jannat Gill, Clinical Research Manager at Jgill@mgh.harvard.edu to learn more.

**LOU** (A one month, investigator and participant blinded study to investigate the efficacy and safety of remibrutinib [LOU064] at multiple dose levels in adult participants with peanut allergy) We are researching the safety and efficacy of remibrutinib (a BTK-inhibitor) in adults ages 18-55 with peanut allergy. The study site is MGH, Boston.

**PROTECT** (A Phase I clinical trial to evaluate the safety and tolerability of VLP Peanut in healthy subjects and subjects with peanut allergy to explore preliminary signals of its efficacy) We are studying the safety and tolerability of VLP Peanut, a therapeutic vaccine, which has been designed to help treat peanut allergy. Healthy adults ages 18-50 weighing over 70kg are eligible for Part A1. Peanut allergic adults ages 18-50 years old are eligible for Part B. The study site is MGH, Boston.

ALK (A phase I open-label trial to assess the tolerability and safety of an up-dosing regimen with a once-daily peanut SLIT-tablet in adults, adolescents, and children with peanut allergy) We are researching the safety and efficacy of a once-daily peanut sublingual immunotherapy tablet (SLIT) that might help lessen allergic reactions to peanut. Peanut allergic individuals ages 12-65 years are eligible. The study site is MGH, Boston.

**SUNBEAM** (Systems Biology of Early Atopy) We are studying factors that put very young children at higher risk for food allergies and eczema. Pregnant women 18 and older planning to give birth at Newton Wellesley Hospital are eligible.

**OWED** (Omalizumab Weight-based Dosing Efficacy) We are researching the efficacy of weight-based omalizumab dosing for food allergy especially for those that have high total IgE that fall outside the current dosing recommendations. Food allergic individuals ages 1-55 years are eligible. The study site is MGH, Boston. This study will start enrollment in February.

Boston Regional Food Allergy Resource Guide



A New Resource! Our Boston Regional Food Allergy Resource Guide was created to help parents and caregivers of children with food allergies locate healthcare providers in the Boston area. Recently published, this guide was created by AAFA New England in partnership with the Mass General for Children's Food Allergy Center, Food Allergy Buddies Program, with funding and support from the Asthma and Allergy Foundation of America, (AAFA). Interested in receiving a free copy of the Guide? Email us at affane@affane.org.

# Thank You To Our Corporate Partners! Your Support Makes Our Work Possible

AAFA New England is grateful for the support of our Corporate Partners, Sponsors and Exhibitors. Their generous support, partnership and participation truly does make our work possible!



# The Thoracic Foundation







# Published with a grant from the Thoracic Foundation

# Asthma & Allergy Bulletin

The Asthma & Allergy Bulletin is published three times each year by the Asthma & Allergy Foundation of America – New England Chapter (AAFA New England) and is mailed to more than 3,000 members of our community.

Information in this Bulletin 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 a endorsement. AAFA New England, including all parties to or associated with this Bulletin, will not be held responsible for any action taken by readers as a result of the Bulletin.

AAFA New England, founded in 1979, is a charitable 501(c)(3) organization whose mission is to improve the quality of life for people living with or caring for someone with asthma, allergies (including food allergies) and related diseases. Serving all six New England states, we are committed to raising awareness about disease management and reducing health disparities through educational programming, patient support, advocacy and support of medical research.

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# How To Support AAFA New England There are many ways!

- Make a one-time, tax-deductible contribution \*
- Set up a recurring monthly donation\*
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- Recommend a grant from your Donor Advised Fund (DAF)
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- Celebrate someone with a tribute
- Attend our Food Allergy Conference & Expo
- Join us at our 2025 Fall Gala and Exhibit
- Support a Team AFFANE runner in the Falmouth Road Race
- Contribute to our Medical Research Grant
- Become a Corporate Partner, Sponsor or Exhibitor

\*Online contributions can be made at asthmaandallergies.org Checks, made payable to AAFA New England can be mailed to:

AAFA New England 25 Braintree Hill Office Park, Suite 200, Braintree, MA 02184

Every Contribution Counts! Thank you!

Have an idea for an article for our Bulletin? Please let us know! Email us at aafane@aafane.org or give us a call at 781-444-7778 Thank you!



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# Have asthma or allergies? Know someone who does? We bet you do!

In the U.S. nearly 28 million people have asthma and more than 100 million people experience allergies (seasonal, food allergies and eczema) each year. Chances are you, or someone you know or love deals with the challenges of living with asthma and/or allergies.

AAFA New England is a community – your community. We are dedicated to helping people with asthma and allergic diseases, and those who care for them. We do this through educational programming, public awareness, support for research and legislative advocacy.

Our community is growing! Join Us!

Visit asthmaandallergies.org to sign-up to receive updates. Help us to spread the word!

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