

Asthma & Allergy Bulletin

ASTHMA AND ALLERGY FOUNDATION OF AMERICA • NEW ENGLAND CHAPTER

Fall Gala

Fall Gala 2024

for life
without limits™

November 1

Join Us!

When: Friday, November 1st

6:00pm – 9:30pm

Where: UMass Club

One Beacon Street, Boston,
32nd Floor

Parking: \$8

**Honoring Three
Champions of the Asthma
and Allergy Community**

**Please join us for a great
evening and connect with
new and old friends!**

**To purchase tickets and
to support AAFA New
England, go to:
[https://e.givesmart.com/
events/CLZ/](https://e.givesmart.com/events/CLZ/)**

September is Asthma Peak Month

See page 7 for Tips
to Manage Asthma
Symptoms.

Staying Safe at School with Food Allergies

By Susan Rudders, MD, MS

The fall can be an exciting and busy time for families with school-aged children but for families of children with food allergies, it can also be a time that requires additional planning and preparation. It has been estimated that in the United States, around 2 children in every classroom have food allergy!



Plan Ahead:

- If your child is starting school for the first time, take time to understand your school district's policies on how they provide a safe environment for food-allergic children.
- Before the start of school, make sure that your school has all of the required forms, plans and medications in place to keep your child safe.
 - Provide the school with a food allergy action plan and medication orders from your doctor or allergist. These forms communicate important information about your child's food allergies and allow your child to take emergency medications to school.
 - Make sure the school has up-to-date emergency medications available at the start of the school year. Be aware of where your child's epinephrine auto-injectors are stored at school, who has access to them and who will give the medications if needed

Consider these tips when preparing for the school year:

- Food exposure can occur in the cafeteria, but it is also important to have a plan in place to prevent accidental exposures in other school settings such as the classroom, school celebrations, art projects and field trips.
 - Speak with your child's teacher(s) about the role of food in the classroom. For example, many classrooms limit food-related celebrations but if needed, you can have a plan in place to send safe snacks with your child.

Continued on page 2

5 Tips for Caregivers Managing Food Allergy Anxiety

By Emilé Baker, LICSW



Parenting comes with its own set of challenges, but for parents of children with life-threatening food allergies, these challenges can feel overwhelming. The constant need for vigilance, fear of accidental exposure, and experiences of social isolation can create a unique form of stress and anxiety that profoundly impacts the well-being of both children and their caregivers. One of the most difficult aspects of food allergy anxiety is that allergies are often invisible and misunderstood by others. This can leave parents feeling isolated, unsupported, and solely responsible for their child's safety, further heightening anxiety and contributing to social disconnection.

Food allergy anxiety is distinct in that some level of anxiety is necessary to manage food allergies effectively. It can be a valuable tool that helps caregivers plan and prepare to avoid allergen exposure. However, when anxiety becomes overwhelming and interferes with daily functioning and quality of life, it becomes problematic. Caregivers experiencing unmanageable anxiety may face chronic stress, hypervigilance, and a pervasive sense of fear and fatigue. They may struggle with sleep, irritability, and social withdrawal, which can, in turn, affect their children, as kids often sense and mirror their caregiver's anxiety. This ripple effect can disrupt the entire family dynamic, impacting relationships between siblings and partners.

Continued on page 2



Asthma and Allergy
Foundation of America®
NEW ENGLAND CHAPTER

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Staying Safe at School with Food Allergies *(continued from page 1)*

- Consider transportation issues - Children ride buses back and forth to school, during field trips and for after-school activities. Many schools have a “no eating” policy on school buses.
- Prepare for Field Trips and Extracurricular Activities - Your child’s food allergy should not prevent him/her from participating in any activities. Plan ahead, so you can address any food allergy concerns that could arise in these special settings.
- Bullying awareness – One third of kids with food allergies report feeling bullied at some point. Talk to your child about bullying and learn about your school’s anti-bullying prevention programs.
- Help your child learn about self-management - For children with food allergies, preventing allergic reactions involves learning to make good choices and advocating for themselves in lots of different settings. Learning these skills takes time and practice. Talking to your child about their allergies at home can help with school routines too.
- Cooperation is key! Many members of the school community work together to create a safe environment for students with food allergies. This group can include the school nurse, teachers, administrators, cafeteria staff, transportation staff, coaches, other parents and your child’s classmates. It is helpful to get to know all of the key people in your school and maintain open communication throughout the school year.



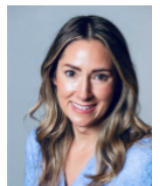
Susan Rudders, MD, MS is an allergist/immunologist at Boston Children’s Hospital and an Assistant Professor of Pediatrics at Harvard Medical School. She is the physician director of the BCH Food Allergy Center at 2 Brookline Place.

5 Tips for Caregivers Managing Food Allergy Anxiety *(continued from page 1)*

Addressing food allergy anxiety in caregivers is crucial when it interferes with daily life. Here are five tips to help caregivers manage their anxiety more effectively:

- 1. Education:** Knowledge is power. Seek information from reputable sources, such as medical advice from your allergist or organizations like the Asthma and Allergy Foundation of America, New England Chapter (AAFA New England), the Asthma and Allergy Foundation of America (AAFA), Food Allergy Research & Education (FARE) and Kids with Food Allergies (KFA). Learning how to prevent accidental exposure and respond to emergencies can empower caregivers and reduce anxiety.
- 2. Decatastrophize:** Assess the likelihood of your worried thoughts. Are you overestimating the risks and underestimating your ability to manage the situation? Would your fears hold up under scrutiny, or are they highly unlikely scenarios? Exploring the validity of catastrophic thoughts can help put things into perspective.
- 3. Reframe Your Anxiety:** Instead of fearing your anxiety, acknowledge that it serves a purpose in planning and preparation. Eliminating all anxiety is not realistic, but recognizing when your thoughts are helpful or unhelpful can make a big difference. Ask yourself, “Is this thought useful to me?” If it is not, try to set it aside.
- 4. Build a Support Network:** Connecting with other parents of children with food allergies can provide emotional support and practical advice. The feeling of being misunderstood can be one of the most painful aspects of managing food allergies as a caregiver. Finding a community that “gets it” is key.
- 5. Prioritize Self-Care:** It is essential for caregivers to take care of their own mental health- remember the oxygen mask goes on you first! This might include seeking therapy, practicing mindfulness, or engaging in regular physical activity to manage stress. Do what feels good to you and make it a regular habit.

Food allergy anxiety is a significant issue, but it does not have to dominate a caregiver’s life. By normalizing some of the anxiety and taking proactive steps to cope, caregivers can create a more balanced environment for themselves and their children. With these helpful strategies, it is possible to navigate the challenges of food allergy parenting with confidence.



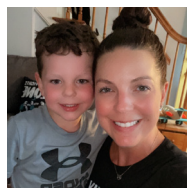
Emilé Baker, LICSW, is an Associate Professor of Practice at Simmons University, School of Social Work and a psychotherapist in private practice in Wellesley, MA. Baker specializes in anxiety and depressive disorders and has a niche expertise in treating food allergy anxiety and anaphylaxis trauma for young adults and caregivers. She also developed and facilitates a virtual, short-term cognitive behavioral therapy group for parents and caregivers of children with life-threatening food allergies.

Team AAFANE Runs the ASICS Falmouth Road Race 2024!

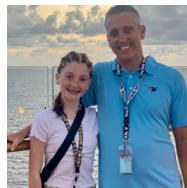


A huge **Thank You** to the members of Team AAFANE who ran the ASICS Falmouth Road Race 2024 on August 18th to support AAFA New England's mission! The team of fifteen runners covered seven seaside miles and raised over \$20,876.36 for AAFA New England's work for the asthma and allergy community!

Meet Team AAFANE 2024:



Nina Olson



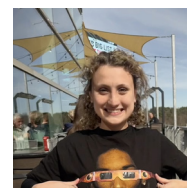
Oliva and
Brian Wolfe



Max Reinhardt



Nicole Arpiarian



Maggie Ault



Casey O'Connor



Sara and
Brian Helmes
(children)



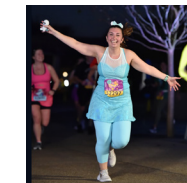
Zach Yusuff



Matthew Hiller



Kelly Dunham



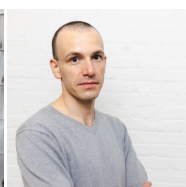
Katie Dimasi



Meghan Neri,
Team Captain



Larry Amara



Ilya Podolyako

We are grateful for each member of Team AAFANE – together, and with your help, we will make a difference!

Three runners share why they ran for AAFA New England in the 2024 ASICS Falmouth Road Race.

Larry Amara:

On October 15, 2023, my brother-in-law, Michael Brown (41), tragically passed away due to an allergic reaction to a bee sting. His loss leaves an indescribable void for us all. However, I find comfort in the belief that participating in events like this will help keep his memory alive. I'm not typically one to participate in races, and Michael knew that well. Yet, when I casually mentioned running this race a year ago, he promised to be there to cheer me on. That promise now fuels my determination and excitement as I prepare to cross the finish line in August. The remarkable efforts of this organization in supporting those with asthma and allergies deeply inspire me. It's a privilege to contribute to their cause and to honor Michael's memory in doing so.

***Team AAFANE's Larry Amara reached the highest fundraising total of \$2,842.05.**

Oliva and Brian Wolfe:

We are so excited to run our very 1st Falmouth Race on behalf of AAFA New England. It's an amazing organization that has helped us through our food allergy journey over the last 13 years. I was diagnosed with life threatening food allergies at 9mos old and asthma when I was 2. It's been challenging for myself and my family but with the education and support of AAFANE we knew we were not alone.

Kelly Dunham:

This will be my third year running for the Asthma and Allergy Foundation of America, New England Chapter. And I couldn't be more honored and grateful! Please help me celebrate this foundation and all the hard work they put into their research, Education, and support to families afflicted. Together we can help make a difference, and save lives.



AAFANE'S Fall Gala 2024 and Exhibit

An Invitation - Tickets are Now Available!

Fall Gala 2024

for life
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November 1



Asthma and Allergy
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Register online
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Honoring Champions of
the Asthma and Allergy
Community

Date: November 1, 2024

Time: 6:00 - 9:30 pm

Location: UMass Club -
One Beacon St, 32nd Floor, Boston

Join us for a
spectacular evening
of conversation,
exhibits, cocktails
and dinner - and an
inspiring skyline
view of Boston!

AAFA New England is Proud to Honor Our 2024 Champions of the Asthma & Allergy Community!



Hans Oettgen, MD, PhD

Allergist and Immunologist and Deputy Chief of the Department of Pediatrics, Associate Chief of the Division of Immunology, and Harvard Medical School Dean for Academic Programs at Boston Children's Hospital.



Aleena Banerji, MD

Allergist and Immunologist and Clinical Director of the Allergy and Clinical Immunology Unit at Massachusetts General Hospital and Professor at Harvard Medical School.



Cindy Guo, CPhT

Certified Pharmacy Technician and Medication Access Coordinator, Pediatrics Specialty Pharmacy at Boston Medical Center.

For Tickets, Sponsorships and Auction Items, visit:
<https://aafa24.givesmart.com/>

Your generous support will enable AAFA New England to help people with asthma and allergies live longer, healthier lives through educational programs, increased public awareness, advocacy and support for research

Asthma and Allergy Foundation of America, New England Chapter is a 501(c)3 organization. Contributions are tax-deductible to the fullest extent of the law

781-444-7778 | <https://asthmaandallergies.org/>

For Tickets and to view Auction Items, visit: <https://aafa24.givesmart.com>



We are thrilled to announce that **Gaurab Basu, MD, MPH**, will present the **Keynote Address** at this year's Fall Gala. Dr. Basu's informative and timely message will focus on "Climate Change and its impact on the health of individuals managing asthma and allergies."

Gaurab Basu, MD, MPH

Primary Care Physician, Department of Medicine, Cambridge Health Alliance Assistant Professor of Medicine and Global Health & Social Medicine, Harvard Medical School Assistant Professor of Environmental Health, Harvard T.H. Chan School of Public Health

Exhibits by participating Fall Gala Sponsors will provide displays that showcase current management therapies for asthma and allergies, so important to all who are impacted by these chronic diseases.



ZULU NYALA
Experience the Magic of Africa

Our Silent Auction will include feature items ranging from theater tickets, hotel and vacation getaways, outdoor adventures, sports tickets, museum and restaurant gift cards, including a HUGE Burton's Grill gift basket, and more! Featured this year is the return of Zulu Nyala to our Silent Auction, an unforgettable safari in South Africa!

Join us! You will have a great night!
Seating is limited - We have sold out for the past few years!

AAFA New England: News & Notes

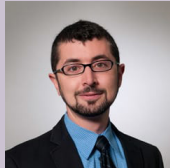
Spring Speaker Series Recap



"Food Allergies: Advances in Treatment:" **Tuesday, May 14, 7-8PM**

Presented by Sarita Patil, MD

Dr. Patil shared exciting new information about advances in food allergy treatment and current and future therapies, as well as clinical trials in progress.



"Food Allergies: Have a Question? Ask the Allergist!"

Wednesday, June 12, 7-8PM

Presented by Michael Pistiner, MD, MMSc

In this interactive webinar, Dr. Pistiner discussed and answered questions about food allergy diagnosis, allergic reaction and anaphylaxis, and helpful tips for managing food allergies.

Information about 2024 Fall Speaker Series will be shared on our website and in our email communications with our community.

All Speaker Series webinars are recorded and can be found at asthmaandallergies.org

If you missed the Spring Speaker Series webinars, or to view previous webinars on topics of interest, go to asthmaandallergies.org – and Stay Informed!

Legislative Advocacy

MA S.1338 /H.2183 An Act to improve food allergy awareness

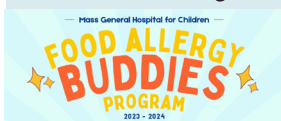
AAFA New England continued its vigorous and unrelenting efforts to move this bill forward and see it passed into law. The bill passed favorably out of the Joint Committee on Public Health and had 79 co-sponsors and moved to the Senate Ways and Means Committee. Despite a concerted and coordinated effort between AAFANE and FARE, the bill did not make it through this legislative session. We commend Nicole Arpiarian for her passion, perseverance and hard work to see this bill passed into law.

NH Senate Bill 555

AAFA New England continued its support of NH SB 555 and participated in a group sign-on letter to advocate for restoring the rebate passthrough mandate language in the bill. This language is needed to help increase access and affordability for patients to needed medicines.

Pharmacy Benefit Manager Reform Act

AAFA New England wrote letters to Senator Markey and Congressman Neal to request their support of Pharmacy Benefit Manager (PBM) reform on the federal level. PBM reform would help ensure patients have fair access to vital drugs and therapies and fair pricing.



AAFANE – MGH Food Allergy Buddies Update

As part of AAFA New England's 2024 partnership with the MGH Food Allergy Buddies Program,

AAFANE developed a comprehensive Resource Guide of medical professionals in the greater Boston area, including allergists, registered dietitians, nurse practitioners, and psychologists who are accepting new patients with food allergy. This Resource Guide will be available later this fall and may be accessed digitally, downloaded and printed.

AAFA New England's Leadership is Growing!

Executive Director News!

AAFA New England is thrilled to announce that Lori Rohleder will assume the position of Executive Director with us as of October 16, 2024! Lori has an extensive background in non-profit development and outreach and a personal interest in the area of asthma and allergies. She is particularly passionate about assuming a position of leadership in a mission-based organization dedicated to making a difference and to have the opportunity to provide support to individuals and families throughout the New England region. Lori, we look forward to October 16 and having you onboard!



Welcome AAFANE's Three New Board of Directors!



Dianna Queheillalt, CPNP, RN, AE-C, Dianna is a certified pediatric nurse practitioner at Boston Children's Hospital, and a certified asthma educator. She is passionate about treating patients with food allergy, eczema, asthma, eosinophilic esophagitis and other allergic conditions. As a parent of a child with multiple healthcare challenges, she enjoys the opportunity to impart her personal and professional knowledge to families to help them improve their quality of life while living with chronic illness.



Emilé Baker, LICSW, Emilé Baker, LICSW, is an Associate Professor of Practice at Simmons University, School of Social Work and a psychotherapist in private practice in Wellesley, MA. Emilé specializes in anxiety and depressive disorders and has a niche expertise in treating food allergy anxiety and anaphylaxis trauma for young adults and caregivers. She also developed and facilitates a virtual, short-term cognitive behavioral therapy group for parents and caregivers of children with life-threatening food allergies.



Meghan Neri, Meghan Neri has been managing food allergies in her home for more than 15 years and, as a former school teacher, is passionate about education and awareness. She started a food allergy support group in 2017, and in 2023 launched a consulting and education business, and saw her book Just One Bite published. She has advocated for improved food allergy legislation in Boston and Washington DC. Her hope is to leave the path easier for those to come.

Welcome the newest member of our Medical Advisory Committee!



Wendy Elverson, RD, CSP, LDN, is Senior Clinical Nutritionist, Center for Nutrition in the Division of Gastroenterology, Hepatology and Nutrition at Boston Children's Hospital since 2003. She has been practicing as a registered dietitian in the area of pediatrics for over 25 years. Helping children and their families living with food allergies is one of Wendy's passions; she is a member of the multidisciplinary teams in the Atopic Dermatitis Center, Food Allergy Comprehensive Evaluation Treatment and Support program, Eosinophilic Gastrointestinal Disorder Program and Growth and Nutrition Program at Boston Children's Hospital.

Research: Opportunities to Get Involved



Boston Children's Hospital
Until every child is well™

- **IDEA** (Investigating Duplimumab's Effect on Asthma by genotype) We are studying if people have a certain genetic make-up (genotype) will respond better to duplimumab. 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://bchasthmaaresearch.com>

Scan to participate



Scan QR code
to learn more



**Massachusetts General
Hospital**

Contact: Jannat Gill, Clinical Research Manager at Jgill0@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. 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.



FDA Approves neffy® (epinephrine nasal spray) to Treat Severe Allergic Reactions

neffy® 2mg is the **first and only needle-free** treatment for type I allergic reactions, including anaphylaxis, and will treat type I allergic reactions, including anaphylaxis, in adults and children who weigh ≥ 30 kg (66lbs).

This is a significant milestone in the delivery of epinephrine! It is compact and easy to carry, and without the need for injection with a needle for treatment, any hesitation to treat anaphylaxis may be removed for many. This means better clinical outcomes may be achieved as well as improvements in quality of life for both patients and caregivers.

Patients can now pre-order neffy® by visiting neffy.com and clicking the "Getneffy now" button at the top of the homepage. The company expects pre-orders to start shipping at the end of September.

There are 2 ways to get a prescription for neffy®:

1. Request a prescription from your current healthcare provider
2. Meet with a physician through a virtual consultation, who can e-prescribe neffy

The **neffyConnect** service provides information about prior authorization, copay savings, insurance coverage support, at-home delivery options, refill reminders, and identifying affordable pricing.

Thank You to Our Corporate Partners

AAFA New England is grateful for the support of our Corporate Partners in 2024. Their generous support allows us to provide valuable resources to help our members live fully with asthma and allergies.



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Health Plan

The Thoracic Foundation



Published with a grant from the Thoracic Foundation

Asthma & Allergy Bulletin

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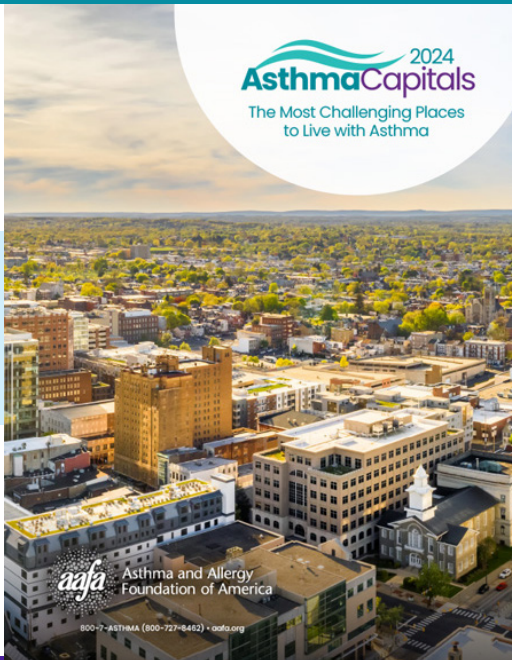
The Asthma and Allergy Foundation of America, New England Chapter, is dedicated to helping people with asthma and allergic diseases, and those who care for them, through education, support for research and an array of services.

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.

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September is Asthma Peak Month

- 27 million in the US have asthma
- Black Americans are 6 times more likely to go to a hospital emergency department than white Americans
- Asthma is the leading chronic disease in children



AAFA's 2024 Asthma Capitals Report ranks 100 cities in the contiguous U.S. based on these health outcomes: asthma prevalence, emergency department (ED) visits for asthma, and deaths due to asthma.

Two New England cities ranked in the Top 20:

- **Springfield, MA** at #4 due to higher-than-average ratings for both asthma prevalence and asthma-related deaths
- **Providence, RI** at #10 due to higher-than-average ratings for asthma prevalence
- **Worcester, MA** just missed the Top 20 ranking at #23 as a result of its high asthma prevalence.

The full Asthma Capitals Report 2024 is available online at asthmacapitals.com

Asthma Management Strategies

Asthma is a chronic disease that affects the airways of the lungs making it hard to breathe. **September** can be a challenging month as several asthma triggers happen all at the same time. Ragweed pollens are highest in September, tree leaves begin to fall and mold counts rise. Respiratory illnesses are common as children have increased exposure to these viruses back at school. Asthma episodes are typically more prevalent during the **third week of September**, giving it the name, "**Asthma Peak Week**".

The goal of asthma management is to keep asthma symptoms under control all year long. Uncontrolled asthma can negatively impact your physical and emotional health, exercise, productiveness at home/school/work, travel plans, and your social life. Be familiar with these strategies and work with your doctor to develop a strategy that is right for you:

- *Reduce exposure to known asthma triggers*
- *Use medicines to keep your airways open – make sure you have your prescribed medicines on hand!*
- *Follow your Asthma Action Plan prepared by your doctor with instructions to help manage asthma symptoms and prevent and control asthma episodes.*

Know your Asthma Zones:

Go: You are breathing well -- **Caution:** You are experiencing some asthma symptoms -- **Danger:** Your symptoms are worsening
Don't have an allergist? For help finding an allergist in your area, visit: <https://allergist.aaaai.org/find/>

Asthma can't be cured, but it CAN be controlled! Be Prepared so that you can manage your asthma symptoms and have a healthy and active quality of life!



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Join the AAFANE Community and Get Involved!

- Receive emails about our Speaker Series webinars and Register to learn from the experts!
- Advocate with us for public policies that will benefit the asthma and allergy community!
- Spread Awareness by participating in our social media!
- Donate to a Team AAFANE Runner in the 2024 ASICS Falmouth Road Race!
- Support AAFA New England: your donations help support our work!
- Join us for AAFA's **Fall Gala 2024** on **November 1!**
- For tickets, visit asthmaandallergies.org!

By joining our community you will receive updates and notifications about research, educational programs and events of interest to you.

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TO HELP PEOPLE LIVE ACTIVE, HEALTHIER LIVES

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& Training**

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Advocacy

**Research
Support**

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through grants and charitable donations

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