# ASTHMA & ALLERGY

## **BULLETIN**

## ASTHMA AND ALLERGY FOUNDATION OF AMERICA • NEW ENGLAND CHAPTER

by Judi McAuliffe, RN



## Join us for our

FALL GALA for life without limits Friday, October 12, 2018 6:00 to 9:30 pm Boston College Club 100 Federal Street Boston, MA Honoring Three Champions of the Asthma and Allergy Community

See pages 4 and 5 of this newsletter for details

Many years ago, I attended a National School Nurse Conference entitled Communicate, Coordinate and Collaborate. As school starts each September, I reflect on that title and my school nurse role as an advocate for the health and safety of children with asthma and allergies.

A school nurse can cooperate with



**BACK TO SCHOOL** 

Back to School with Asthma and Allergies





parents, physicians and students and coordinate a healthcare plan that can be communicated to school staff, thereby allowing the student with asthma and food allergies to be the best that he/ she can be. Up-to-date information will allow the nurse to adjust the daily management and assist the teacher/staff in recognizing and handling an emergency situation.

(continued on page 3)

## ASTHMA MANAGEMENT

## Be Smart and Breathe Easy Program

AAFA New England is delighted to report that in April 2018, consulting partners, Jackie Rodriguez-Louis, Lillyana Hebbert, and Meenakshi Verma-Agrawal began work to create the Be Smart and Breathe Easy Program, an asthma program for inner-city school nurses and custodial staff. The goal of the program is to improve outcomes for students with asthma in Boston Public Schools. The program aims to reduce school absenteeism due to asthma, reduce asthma triggers in schools, and increase understanding of disease management and

treatment. Towards this end, our consultants have:

- Researched literature for updates and best practices in asthma management pertinent for program development, reviewed existing materials and other program models, and collected background information from important stakeholders and community partners,
- Reviewed current data including, IPM (Integrated Pest Management) Indexes and school asthma rates,
- Identified and held meetings with key collaborators/

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## Asthma and Allergy Foundation of America® NEW ENGLAND CHAPTER

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David Guydan

## FROM OUR NEW EXECUTIVE DIRECTOR

## A Letter to the Asthma & Allergy Community

## from our new Executive Director

#### Dear Readers,

This newsletter marks the beginning of a new era, a new trajectory for the Asthma and Allergy Foundation of America, New England Chapter. The Board of Directors has performed remarkably well over the last two quarters to position our organization on a sound set of footings, financially and



programmatically, that will power AAFA New England's combination of education, advocacy and support to make meaningful differences in the lives of so many who are impacted by the effects of asthma and allergies.

Last month, I was asked by the Board to assume the role of Executive Director of AAFA, New England. I am honored to be in a position to use my experience from both for-profit and nonprofit Boards and organizations to fulfill our mission, together with our exceptional Board of Directors, Medical Advisory Committee, dedicated volunteers, corporate and foundation sponsors, and other constituencies. An early objective of mine will be to listen to the voices of our stakeholders and focus our near-term efforts on what is most compelling to our supporters.

AAFA New England's mission resonates with me on an emotional level, since I live with a host of environmental allergies. Years ago, I experienced anaphylaxis. Through seeking experienced medical help, understanding the causes of my reactions, and using appropriate remedies, I have felt in control of my allergies for decades. For people who currently suffer from allergies and asthma, and their families who share in the inevitable anxieties and who live in hope of cures, your journeys are made better by the information and resources of AAFA New England.

In upcoming months, I will speak personally to many of our newsletter readers to learn your stories and to hear your needs and interests. What do you care deeply about and how can AAFA New England become more relevant in your daily lives? How can AAFA New England build on its strengths and ignite the collective imagination to realize "what might be?" Please accept my open invitation to contact me at the AAFA New England office (781-444-7778) or send me an email (david@ aafane.org) to introduce yourself and relate your story.

Meanwhile, I hope you all are following our fall line-up of important events, designed to enhance AAFA New England's ability to work on behalf of people suffering from the effects of asthma and allergies throughout the six New England states.

Mark your calendars for our Fall Gala, called "for life without limits™." On Friday, October 12th, from 6:00 to 9:30 p.m., at the Boston College Club, 100 Federal Street, Boston, join me as we honor three Champions of the Asthma and Allergy Community. See the Gala information in this Newsletter, donate via our website at www.asthmaandallergies.org, and be there for what promises to be a memorable evening. I look forward to meeting many of you on October 12th so that I can thank you personally for your good work and generous support of AAFA New England.

Thank you for embracing our mission: "To improve the quality of life for people with asthma and allergies in all six New England states through education, training programs, public awareness, advocacy, and support for research."

Warm regards,

David Guydan Executive Director

## BACK TO SCHOOL (continued from page 1)

#### Everyone has a role to play!

Parents should contact the school nurse and meet before school starts. Discuss "Triggers" for asthma or food allergies. Be specific: viral infections, exercise, cold air, weather fluctuations, laughing or crying and all foods listed with testing. Symptoms: coughing, shortness of breath, wheezing, skin pallor or hives, etc. Treatments: medications (list all that are taken at home and at school with expected effects, when and how they should be taken). Rest. Follow doctor's orders. Remember to request physician's orders for medications and treatments. The nurse must have signed physician orders.

The nurse should be a good listener, gathering all the above information and explaining to the parent the school policies. The nurse, with the parent, will write a healthcare plan.

*Triggers:* the nurse will assist the classroom teacher in identifying and removing possible allergens. She will educate the cafeteria staff about food allergies and the use of an epinephrine auto-inject device. The nurse will also speak with the physical education teacher about anticipated use of inhalers before class. If weather is a triggering factor, the nurse will discuss recess alternatives with the parent, depending on school policies.

Symptoms and treatment: the nurse should "teach the teacher". In Massachusetts with certification from MDPH a nurse can train all staff members the use of epinephrine auto-injector devices for the students with a known diagnosed allergy (food, stinging insect, medicine or latex). Parents can reinforce epinephrine auto-injector administration at teacher conferences and share additional information about any changes in the child's condition or treatment with a telephone call, note or email. Parents should stay in contact with the nurse, too.

Each school system has its own policy with the regard to medications: however, most policies require that all medications be delivered to school by an adult, that medications be in a prescription-labeled container and be accompanied by a signed permission and instruction form from the physician and a signed parent permission form. With the agreement of the physician, parent, student and school nurse, the self-carry and administration of prescribed inhalers and epinephrine auto-injectors are allowed.

School nurses are great resource people. Many plan in-service education for school administrators, all staff and parents. Others have chaired Asthma and Allergy Education Support Groups. Administrators/teachers, through inservice education, are alerted to the signs and symptoms of asthma and food allergies and can be prepared for emergencies. They are in position to set standards for air quality and the purchase of art, science and cleaning supplies.

Administrators, school staff (including cafeteria and custodial), nurses, physicians and parents should Communicate, Cooperate and Coordinate. Together they can protect and promote the health and safety of the student with asthma and allergies. With that, the student will feel safe, well cared for in school and have a positive educational experience.

Judi McAuliffe, RN, NCSN, a Pembroke, MA school nurse for 40 years, has been a member and clerk of the AAFA/NE Board of Directors for over 25 years, including 6 years on the National Board. She chaired an Education Support Group for 10 years and is a presenter of the Asthma and Allergy Essentials for Childcare Providers and Parents.

## AAFA New England: Notes on Epinephrine Auto-Injectors

There have been several challenges related to epinephrine auto-injectors over the past few years. Costs have skyrocketed. There have been several recalls and also shortages reported, particularly at the critical back-to-school time. On a more positive note, most states have laws or guidelines in place that allow schools to stock epinephrine and several states have made it a requirement. In addition, a second generic version of the EpiPen has been approved by the FDA, although what minor variations this may have from the brand name device and whether this will impact the price of epinephrine autoinjectors are not yet clear. Also, as of August 21st the FDA has extended the expiration date of some EpiPens and the authorized generic version (manufactured by Meridian Medical Technologies) to help address supply issues. See: https://www.fda.gov/Drugs/DrugSafety/ DrugShortages/ucm563360.htm

Training devices are available for all forms of epinephrine auto-injectors. If your auto-injectors do not come with a training device then request one from the device manufacturers. In addition, instructional videos are available online through the device manufacturers. The primary care or allergy clinician and/or one of their clinical staff should review how and when to use the epinephrine auto-injector at the time of the original prescription and revisit this at follow-up visits. All patients should also have a food allergy action plan updated yearly that outlines how to treat reactions including anaphylaxis. Use your training device and food allergy action plan when training babysitters, relatives, or any person responsible for caring for your child.

Patients should have two epinephrine auto-injectors available at all times, since more than one dose may be needed to treat a reaction or there may be technical problems with administration of the first dose. Ideally, epinephrine autoinjectors should be replaced by their expiration date. However, it is better to use an expired epinephrine auto-injector than none at all. Keep in mind though that schools cannot accept expired medications.

Finally, if you have questions about your epinephrine auto-injector, don't hesitate to ask your doctor or nurse.

## AAFA New England: NEWS & NOTES

## MSIC CHARITY GOLF TOURNAMENT

A very sincere thank you to our corporate partner, MSIC, for holding its Charity Golf Tournament on September 10 to benefit AAFA New England! We greatly appreciate the generous support of our friends, and are pleased to report that we exceeded our expectations for sponsorships and other

donations from the event! Golfers hit the course during the day, and participants enjoyed a celebratory dinner which capped the evening.



#### SUMMER SPEAKER SERIES RECAP

Jennifer LeBovidge, PhD and Karol Timmons, MS, CPNP shared important information in their discussion on atopic dermatitis during their talk, "Managing Your Child's Atopic Dermatitis: Causes, Treatment Strategies and Practical Coping Tips", on July 11 at Boston

Children's, Waltham. Attendees also benefitted from the informal



question and answer session held at the end of the evening.

## AAFA NEW ENGLAND BOARD MEMBER CHAIRS THE NEW ENGLAND SCHOOL NURSE CONFERENCE, MAY 4-6

AAFA New England Board Member Judi McAuliffe, RN, chaired the New England School Nurse Conference



2018 held in Plymouth, MA on May 4-6. The conference was hosted by the Massachusetts School Nurse Organization in partnership with the Northeastern University Health Academy (NEUSHA). This vital conference was attended by school nurses from all areas of New England, and covered a wide variety of topics pertinent to school nursing. Well done, Judi!

#### FALL GALA: for life without limits

We look forward to celebrating with you on October 12 as



we proudly honor three distinguished Champions of the Asthma & Allergy Community: Senator Cynthia Creem, D-Newton, Wanda Phipatanakul, MD, MS, Boston Children's Hospital, and Wayne Shreffler, MD, PhD, Massachusetts General Hospital. Enjoy delicious food, refreshing cocktails, the smooth sounds of the Berklee Jazz Trio and spectacular views from the 36th floor of the Boston College Club, at 100 Federal Street, Boston. Festivities begin at 6:00 pm. Don't miss this memorable evening! For ticket and sponsor information, please go to our website, www. asthmaandallergies.org or call 781-444-7778.

## BE SMART AND BREATHE EASY ASTHMA PROGRAM (continued from page 1)

stakeholders in various fields of education, support, and advocacy including school administrators, representatives from Boston Public Schools, MassCOSH, Boston Children's Hospital, and Boston Public Health Commission,

## SANOFI GENZYME 🎝

- Selected three schools for program implementation; an elementary school, middle and high school for cross-sectional impact (Mission Hill, Boston's Teachers Union, and Exell High School), identified the school nurses and custodians at these schools,
- Developed a working draft and timeline for program implementation and other materials including an Asthma Fact Sheet and Environmental Checklist.



Over the next month, Jackie and her team plan to meet with the nurses, custodians and administrators in the three schools that are targeted for the asthma program. They will complete all components of the program, translate all materials into Spanish to allow students and staff who learn better in their native Spanish language to benefit as well from the program, and begin implementation in September. The program will be concluded in December 2018 and a final report will be submitted to AAFA New England in January 2019.

Consultants: (from left to right) Meenakshi Agrawal, Lillyana Hebbert, and Jacqueline Rodrigues-Louis

## AAFA NEW ENGLAND HONORS THREE CHAMPIONS OF THE ASTHMA AND ALLERGY COMMUNITY

Senator Cynthia Stone Creem (D-Newton), Senate Majority Leader, serves the First Middlesex and Norfolk District. Senator Creem has served in a public



capacity for more than 30 years, first as a member and President of the Newton Board of Aldermen, and then as a member of the Governor's Council prior to becoming State Senator in 1999. She received her J.D. from the Boston University School of Law.

She has served in a leadership role on many high-profile issues, including a landmark law legalizing stem-cell research, which also boosted our state's

#### Wanda

Phipatanakul, MD, MS, has dedicated much of her career to clinical research aimed at reducing and preventing asthma and allergic diseases in children, particularly innercity children. She



directs the Asthma Clinical Research Center at Boston Children's Hospital and is a Professor of Pediatrics at Harvard Medical School.

Dr Phipatanakul earned her medical degree from Loma Linda University and joined the faculty in the Division of Immunology and Allergy at Boston Children's Hospital and Harvard Medical School, where she has

Wayne Shreffler, MD received his MD and PhD degrees from New York University and his Pediatrics training at the Albert Einstein



bio-tech economy and successfully sponsoring legislation on food allergies. Senator Creem sponsored S228 which would require schools to develop food allergy plans at school, and she authored the 2008 law which increased food allergy awareness and training in Massachusetts restaurants.

Among her top priorities since entering the Legislature, Cindy has been the leading advocate for restoring judicial discretion in sentencing and eliminating across-the-board mandatory minimum sentences, and for increasing safeguards for gun ownership.

She served as Chair of the Criminal Justice Committee from 1999-2003, and from 2003-2008, as Chair of the Revenue Committee, when she served on a commission whose

remained for the past 18 years. She holds a Master of Science in clinical epidemiology from the Harvard School of Public Health.

Dr. Phipatanakul has built a deep network of community relationships, and she conducts both school- and home-based asthma studies with inner-city children. Her work was the first to document the relationship between mouse infestations in urban apartments and asthma; she was also the first to comprehensively evaluate how allergen exposures at school affect allergic disease outcomes in children, adjusting for exposures at home. She leads a comprehensive National Institutes of Health (NIH)funded school-based environmental trial, the School Inner-City Asthma Intervention Study.

College of Medicine. He completed his fellowship in Allergy & Immunology at the Mount Sinai School of Medicine in 2003 where he was mentored by Drs. Hugh Sampson and Lloyd Mayer, and established himself as a researcher of immune mechanisms of food allergy and asthma. He joined Massachusetts General Hospital and Harvard Medical recommendations were enacted to promote economic growth and benefit Massachusetts companies. As Senate Chair of the Joint Committee on Judiciary from 2009 -2013, Cindy successfully shepherded legislation reforming the Probation Department, and during 2013-2014, as Chair of Senate Post-Audit and Oversight Committee. During the 2017-2018 session, as one of three Senate members on the Criminal Justice House-Senate Conference Committee, she helped to secure important reforms to the state's policies.

Currently, as Majority Leader, she places a high priority on issues including: Criminal Justice Reform; Health Care; Energy; Environment; Women's Issues; Civil Rights; Education; and Revenue.

Dr. Phipatanakul is the Boston pediatric principal investigator for the NHLBI AsthmaNet and the Severe Asthma Research Program and the PreCISE network. She conducts multiple clinical studies related to asthma adherence devices and therapeutics, food allergies, allergic rhinitis and atopic dermatitis. As a practicing physician at Boston Children's, she cares for children and adults with allergies, asthma and immunologic diseases and is a sought-after speaker both nationally and internationally. She has authored over 200 peer reviewed publications in scientific journals, including JAMA and the New England Journal of Medicine. She was recently elected to the American Society for Clinical Investigation.

School in late 2009 to establish a new translational research and clinical care center focused on food allergy, and he became Division Chief of Pediatric Allergy and Immunology in 2011.

The food allergy program is an integrated research and multidisciplinary clinical effort to advance the *(continued on page 6)* 

## CHAMPIONS OF THE ASTHMA AND ALLERGY COMMUNITY

## (continued from page 5)

care for patients and better understand the pathogenic mechanisms of IgEmediated hypersensiivity in the context of food allergy. The Shreffler laboratory focuses on the characterization of cellular and humoral immune response to dietary antigens and the mechanisms of allergen-induced Th2 sensitization and oral tolerance. Areas of active investigation include 1) the mechanisms of allergenic dendritic cell (DC) activation by allergens and the DC signals that induce Th2 differentiation and primary IgE sensitization; 2) the role of regulatory and other CD4 T cell subsets in natural and immunotherapy-induced oral tolerance; and 3) the role of IgE and non-IgE antibody diversity on IgE-dependent effector cell activation and its regulation.

Dr. Shreffler has authored more than 70 papers, maintained continuous NIH and other research funding since 2007, served on the editorial board of the Journal of Allergy and Clinical Immunology and as reviewer for numerous journals and grant study sections / committees. He was elected a Fellow of the AAAAI in 2009.

## **RESEARCH UPDATE: OPPORTUNITIES TO HELP**

## ASTHMA PREVENTION STUDIES AT BOSTON CHILDREN'S HOSPITAL

Does your child have asthma, allergies or atopic dermatitis? If you are interested in PREVENTION, then you may want to learn more about the following two study projects being conducted at Boston Children's Hospital:

\*VITD (Vitamin D and Asthma Study)

The goal of this study is to find out if oral treatment with high doses of Vitamin D in children 6-14 years old who have asthma, take daily asthma medication and have low levels of vitamin D, will decrease asthma symptoms.

#### \*PEPR-IOF (Asthma Study)

The goal of this study is to find out if the information provided by a pedometer could be used as an Asthma measure. This study is for children 8-17 years old that have asthma. There are two (2) visits to the clinic and you will be asked to answer online questionnaires for three (3) weeks, and to wear a pedometer for five (5) weeks. If you are interested in having your child be a part of one of these clinical trials, please call 857-218-5336, or email asthma@childrens.harvard. edu, for more information. Research participants and their families will receive education and other benefits.

## PEANUT ALLERGY STUDY

## This study is

being conducted to look at the safety and efficacy of the Viaskin Peanut Patch<sup>®</sup> in children. This patch tries to make children less sensitive to peanut by continuously delivering small amounts of peanut protein through the skin. Children who may be eligible must be 1-3 years old with a physician-diagnosed peanut allergy with documentation in the child's medical records. This study involves twelve (12) visits over twelve (12) months at Boston Children's Hospital, peanut food challenges at the beginning and end of the study, skin prick testing and blood drawn four (4) times during the study. Compensation will be provided at the study visits.

For more information about this study, contact EPITOPE Study Team by emailing: Foodallergystudies@ childrens.harvard.edu, or call 617-355-4301.

## ATOPIC DERMATITIS STUDY

Boston Children's Hospital is currently looking for patients who have severe Atopic Dermatitis (AD) to participate in an investigational drug trial. Children may be eligible if they are between six (6) months to five (5) years of age, have been diagnosed with Atopic Dermatitis, and have had Atopic Dermatitis for at least six (6) months.

For more information about this study, contact Felice Chan, Study Research Assistant, at 617-355-4349.



## THANK YOU TO OUR CORPORATE PARTNERS

AAFA New England is grateful for the support of our Corporate Partners for 2018. Their generous support allows us to provide valuable resources to help our members live life fully with asthma and allergies.



# **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.

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Asthma and Allergy Foundation of America®

NEW ENGLAND CHAPTER

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## AAFA New England ACCOMPLISHMENTS

Be Smart & Breath Easy" 2018 Asthma Education Project: a 9-month initiative working with school nurses and custodial staff in Boston inner-city schools to improve the outcome of students with asthma. Made possible through a grant from Sanofi.

#### 2017-2018 Speaker Series:

• Food Allergy Management at School, Speaker Michael Pistiner, MD, at Newton-Wellesley Hospital.

• Bronchial Thermoplasty, A Minimally Invasive Treatment for Asthma, Speaker Carla Lamb, MD, at Lahey Medical Center, Burlington.

 Eating Out With Food Allergies - Your Questions Answered, Speakers Tara McCarthy, RD, and Chef Nick Harron, at Evviva Cucina, Beverly.

• Managing Your Child's Atopic Dermatitis, Speakers Jennifer LeBovidge, PhD and Karol Timmons, MS, CPNP at Boston Children's Hospital, Waltham.

Kyle Dine Family Concert and Expo -Needham High School.

#### Asthma & Allergy BULLETIN:

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#### **Research Support:**

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opportunities for asthma and allergy studies being conducted in the New England area.

• Facilitate meetings between research investigators and interested stakeholders.

#### Advocacy:

• MA SB 228: An Act to Establish Food Allergy Plans - Supported

• MA HB 291: An Act Authorizing the Establishment of a Commission to Evaluate Student Health - Supported

• NH HB 443: Prohibiting Prescription Drug Manufacturers from Offering Co-Payment Reimbursement - Opposed



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