

ASTHMA & ALLERGY

BULLETIN

ASTHMA AND ALLERGY FOUNDATION OF AMERICA • NEW ENGLAND CHAPTER

Save the Dates!



Fall Gala 2019
Celebrate AAFA New England's
40th Anniversary
Friday, October 25, 2019



See details about our Winter/Spring
2019 Speaker Series on the
back page of the Newsletter.

BIG DATA AND THE VALUE OF DIGITAL INNOVATION

by Jyotsna Mehta, Founder, Keva Health

Big data is an oft-quoted but sometimes misunderstood concept in the world of digital health. Generally, big data refers to datasets that are simply too large and complex to be analyzed by traditional data processing methods. A popular definition by Gartner, a leader in data and analytics, states "big data is high-volume, high-velocity and/or high-variety information assets that demand cost-effective, innovative forms of information processing that enable enhanced insight, decision making, and process automation." Gartner defines big data in terms of three Vs: Volume, Velocity, and Variety. Volume signifies the enormous size of datasets being generated and stored; Velocity indicates the ever-increasing speed of data generation and processing; and Variety refers to the heterogeneity of structured and unstructured data that

are being produced. In healthcare, there is a plethora of data types and formats that are routinely collected in hospitals, research labs, family doctors' offices, pharmacies, and a whole host of other locations. However, the challenge becomes how to process and extract key insights and trends from this deluge of data to improve health outcomes and reduce costs for patients through evidence-based recommendations.

Asthma is the most common chronic disease among children and adolescents. There are about 300 million people suffering from asthma globally, and it is one of the costliest treatments in the U.S. Asthma is responsible for about 2 million emergency department visits and about 3500 deaths annually. With the increasing amount of data being collected through various

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THE INTERNET AND FOOD ALLERGIES: A PLACE AT THE FOOD ALLERGY TABLE

by Elisabeth Stieb, RN, BSN, AE-C

The Internet provides almost unlimited food allergy resources that materialize with the click of the mouse. Food allergy providers expect patients and families will research the Internet to supplement their medical recommendations. The food allergy community often uses the Internet to seek information, share a social support system and research management strategies. Many food allergy sites are enormously beneficial while others promote unproven therapies, offer inaccurate information, provoke anxiety, or appear to be potentially dangerous.

Seeking information: Accurate, up to date information catering to food allergies is accessible through dozens of advocacy websites, such as AAFA New England, Asthma and Allergy Foundation of America and Kids with Food Allergies. Information found on these sites is monitored, updated and follows a specific mission statement and guidelines. Oversight, integrity and transparency are the principles that direct the major advocacy and medical organization sites. Information presented is trusted health material designed to empower patients and families through education and support.

A Social Support System: The shared story is a new concept in medicine and on the web, but obviously an ancient tradition. It is the shared story that makes the Internet, bloggers, Facebook groups, online support groups, etc. so attractive. It's an instant connection with a human commonality. We can view posts sharing a seemingly fairytale story when the universe unites to provide a child with a magical food allergy friendly day, and we all rejoice. For others who post, the menacing big, bad wolf is lurking at the door and we all feel the anxiety and fear of a reaction.

There are wonderful social media sites that provide positive support, accurate information and maintain oversight for inappropriate posts according to their guidelines. They are respectful of members, not alarmists and provide a safe space for families with food allergies.

(continued on page 3)

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David Guydan

Dear Readers,

One part of my background during my for-profit years was in the field of collecting, managing and distributing large databases for use by banks, brokers, money managers, investment banks and others. Over time, technology made these databases available, not just to institutions, but to individuals as mainframe computers gave way to micro computers and, now, personal devices connected to the Internet and powered by apps that support thousands of tasks.



There are few areas of human endeavor today that are untouched by technology which is a theme of this edition. In her article, "The Internet and Food Allergies," Elisabeth Stieb reminds us to be cautious about food allergy resources abundantly available in cyberspace, while suggesting strategies for finding trustworthy information online. In "The Importance of Big Data and the Future of Digital Innovation," Jyotsna Mehta explains the use of "big data" in healthcare, generally, and in asthma management, specifically.

Please take note of Dr. Michael Pistiner's "Food Allergy Management Boot Camp" for parents and caregivers of food allergies. Attend in person at Massachusetts General Hospital, join the interactive group sessions live-streamed, or view the recordings of each Boot Camp on Facebook.

Jan Hanson, AAFA New England Board President, summarizes the conclusions and recommendations of our Sanofi Genzyme-sponsored "Be Smart and Breathe Easy Program," citing the many positive outcomes of the Program and holding out the possibility of expanding such asthma education and asthma trigger remediation in our children's schools.

Our Board of Directors and our membership are committed to advocacy initiatives so that we can impact policy or influence state legislatures on bills that affect our community. Board member Bob Stoker is pounding the pavement in New Hampshire and Massachusetts to find ways to lower prescription costs. One of our Honorees at the Fall Gala 2018, Senator Cynthia Creem of Massachusetts, is a long-time proponent of improving food allergy policies through meaningful legislation. See two bills that she introduced in January which AAFA New England is supporting and learn how you, too, can make your voice heard.

Check out our "Research Update" to learn about new research in the field of asthma and allergies and opportunities to help through involvement in clinical trials and live studies.

We hope you enjoy reading and find useful our Asthma & Allergy Bulletin. We welcome your comments. Let me know what you think about our Newsletter, offer topics you'd like to see in future editions, or suggest ways to improve it. Send me an email at: david@aafane.org.

Warm regards,

David Guydan
Executive Director

BIG DATA AND THE VALUE OF DIGITAL INNOVATION (continued from page 1)

sources, it is possible to analyze the data and provide real time insights. Administrative healthcare claims and electronic health record data can be used to identify those patients with higher risk and to study treatment patterns among specific sub-groups. These types of information would allow healthcare providers to deliver better quality care and for patients to prevent the incidence of emergency room events. Using blood and sputum samples collected from a large number of patients, researchers are able to identify different sub-types of asthma and facilitate the research and development of new treatments.

Patient experience with medical treatments recorded in electronic health records, insurance claims, patient registries, and newer mobile technologies can help shape the design of clinical research, expand product use, and assess the efficacies of new therapies in the real world.

Big data also helps in asthma management. The development of smartphones and smart devices makes it possible for collecting data securely at any time and providing real-time feedback. Applications on iOS or Android devices can help to manage disease interactively, help

patients to implement individual action plans, provide personalized reminders, and send alerts based on their individual risk profiles.

Hence, big data and digital tools focused on the detection, prevention, and management of specific chronic diseases (including asthma and allergies) will generate a growing body of evidence that demonstrates their impact on human health and that will help extrapolate potential cost savings in our healthcare system. Its adoption requires patients, physicians and payers to embrace the available technologies and engage to improve patient outcomes and reduce costs.



Jyotsna Mehta, Founder, Keva Health, is an entrepreneur in digital health and analytics bringing over 18 years of experience in academia, regulatory affairs, and the pharmaceutical industry. The parent of a child with asthma, Jyotsna founded and developed Keva Health Advisor, a digital platform that uses artificial intelligence to help asthma patients manage, track, alert and recommend treatment options. www.kevahealth.com

LEGISLATIVE ADVOCACY

In Massachusetts, State Senator Cynthia Stone Creem (D-Newton) is a long-time proponent of improving food allergy policies. In January, Senator Creem filed two bills of consequence:

- SD618, will require schools to have Food Allergy and Prevention Plans, and require training for school personnel on how to prevent allergic reactions, and procedures to follow if an allergic incident occurs.
- SD680, an act to improve food allergy awareness, builds on existing law, by requiring restaurants to designate an individual with knowledge about food allergy issues to coordinate food service for customers who identify themselves as having food allergies.

Editor's note: one of our constituents, Nicole Arpiarian, the mother of a child who had a life-threatening allergic reaction, has for the last year dedicated herself to fight for positive actions that will make restaurants safer for those with food allergies.

In New Hampshire, Robert Stoker, AAFA New England Board Member, has been advocating that, if anything, copay cards reduce the costs of pharmaceuticals to both insurance companies and patients. While the insurance industry testified otherwise at hearings on the matter, the legislative committee hearing the testimony recommended that copay cards/coupons should continue to be allowed. Clearly a win for AAFA New England's constituencies.

In Massachusetts, a bill to outlaw the use of copay cards is now being considered. In addition to AAFA New England's plan to contact legislators and testify before committees, individuals should contact their own state representatives, voicing strong support for continuing the use of copay cards to keep lower the cost of prescriptions. It is with your help that we can have positive impacts on the policies that affect us all!

THE INTERNET AND FOOD ALLERGIES (continued from page 1)

Many Facebook groups, however, do not have any administrative oversight. Members post inaccurate, discrepant information. Repeatedly, they post videos or photos seeking medical advice, which is then provided in multiple conflicting responses. Some post videos of their child experiencing a systemic reaction rather than following their food allergy action plan or seeking emergency care. It is a disturbing trend that goes unchecked with no recourse. Being inundated with frightening or negative social media affects quality of life. Anxiety can spike and misinformation is reinforced.

Management Strategies: An abundance of helpful information exists on the web. Food allergen avoidance, label reading strategies, manufacturer recalls, research and innovation, how to manage food allergies in schools and childcare, dining out with food allergies, recipes and substitutions are some of the myriad management strategy offerings.

Finding a balance of food allergy information online is critical to health and emotional wellbeing for caregivers and children. Find your sweet spot by knowing where the best information for your family is posted. There is a place for everyone at the food allergy table as we all share in the bounty of information accessible, but be careful not to overindulge on the unhealthy offerings.



Elisabeth (Lisa) Stieb RN, BSN, AE-C is a food allergy nurse and certified asthma educator at Massachusetts General Hospital Food Allergy Center for 19 years. She is mother of two sons with food allergies and has been involved with food allergies for 28 years.

AAFA New England: NEWS AND NOTES

**AAFA New England Gala
October 18, 2018
Boston College Club**



Our first Fall Gala was a huge success and a memorable evening! More than 120 guests were greeted by the Boston skyline, a glowing sunset, and the rich sounds of a jazz trio.

Our Honorees (pictured above, Senator Cynthia Stone Creem - center - with AAFA NE board chair, Jan Hanson and AAFA NE executive director, David Guydan, and right, Dr. Wayne Shreffler and Dr. Wanda Phipatanakul) were recognized for their outstanding work in helping people with asthma and allergies.



Thanks to the generosity of our sponsors, attendees and others, we exceeded our funding expectations and garnered

the support we need to continue our important educational programming, support services, Speaker Series, and advocacy on behalf of our valued asthma and allergy community (AAFA New England board members pictured above).

**Massachusetts Health Council Award's Gala
December 8, 2018, Seaport Hotel**



David Guydan and David Martin, Mass Health Council Executive Director

As the largest and oldest health council in the U.S., the Mass Health Council promotes policies and programs that enable healthier lifestyles, wellness and preventative care. Asthma is cited among the preventable health conditions in its annual report on the "Common Health for the Commonwealth." The Mass Health Council supports the goals of research and changes to policy and practice aimed at reducing risk factors for the complex chronic disease, asthma.

New England Society of Allergy (NESA) Fall Meeting

On October 20, 2018, Board Member Bob Stoker and David Guydan, attended as exhibitors at the NESA Fall Meeting in Plymouth, MA. Moderated by Lisa Bartnikis, MD, (pictured right) AAFA New England Board Member and Member of our Medical Advisory Committee, the agenda provided CME and CEU accredited presentations for NESA members and their nursing and support staff. Our presence afforded us visibility with an important constituency that is highly supportive of our programs.



Boston Red Sox Peanut Allergy-Friendly Program at Fenway Park



In November, a group (see photo) representing AAFA New England met with Fenway Park officials regarding their Peanut Allergy-Friendly Program. During the 2019 baseball season, the Red Sox will set

aside the "right field terrace" with proper preparations and care to create an environment at these games safe for fans who are allergic to peanuts. The section accommodates up to 160 fans, has controlled access, and is close to concession stands that for these games are Peanut Allergy-Friendly. Our team made a number of recommendations including care in washing down the section designated prior to game time, training of food service managers and servers, communication of protocols among staff, and offering wipes if families elect to wipe down their own space.



Want to take your family to a ball game? Peanut Allergy-Friendly games will be held on April 28, May 12, June 9, June 23, August 11 and 18. A mid-July date is also planned. To get on the Red Sox Peanut-Free mailing list, send an email to: PeanutAllergy@redsox.com.

SUMMER CAMP: SAFETY AND SUCCESS

by Sue Lein



Class trips, sleepovers and parties make you very nervous, right? And summer camp, well, that would

never be possible... But what if it were?! Your child with food allergies or celiac disease can go to camp. Asking questions and preparing = safety and success. By using the same vigilance you approach making dinner, your child can have a safe and joyful camp experience.

First, make a list of your requirements – day/overnight, specialized or general, single sex, coed, etc. Then, prepare your list of questions. Here are my top 10 to ask:

1. Have they supported other food allergy and celiac children? Get references.

2. Who prepares the food? What is their training?
3. How do they prevent cross contamination?
4. What is the camp's policy about outside food and packages?
5. How is food managed on trips?
6. Review a copy of the menu with the kitchen staff. Get a list of all gluten free and allergy safe products available.
7. How will you have access to the camp director, health staff and kitchen?
8. Be sure your child can read any label they want and ask questions about the food.
9. Day camp – who supervises the young children? What about transportation?

10. Describe the staff training and epinephrine procedures.

You will be able to tell the camp's knowledge and commitment to support children with food allergies and celiac disease from the answers to these questions. A positive experience will prepare you and your child for future independence.



Sue Lein is the Owner & Camp Director of Camp Emerson in Hinsdale, MA. Camp Emerson is a Food Allergy Specialist Camp and has been helping children with food allergies and celiac

disease for over 20 years. Contact Sue at hello@campemerson.com, or call 800-782-3395 and mention this article.

AAFA New England: PROGRAM UPDATES

Be Smart and Breathe Easy Program Makes a Positive Impact on Three Boston Inner City Schools by Jan Hanson, MA, AAFA New England Board President

In April 2018, Jackie Rodriguez-Louis, Lead Consultant, and her consulting partners, Lillyana Hebbert and Meenakshi Verma-Agrawal, were contracted by AAFA New England to create and implement the Be Smart and Breathe Easy Program asthma program for Boston inner city schools. Two key and unique features of this asthma program, as compared with other school asthma intervention programs, are that it was designed to work with both Boston school nurses and custodial staff, and it highlighted the need for remediation



Consultants: Meenakshi Agrawal, Lillyana Hebbert, Jacqueline Rodriguez-Louis

of mouse presence, which recent study results showed to be the most significant environmental asthma trigger at schools. The overarching goal of the program was to improve outcomes for students with asthma in Boston Public Schools (BPS) by reducing asthma triggers, increasing understanding of disease management and treatment, and ultimately reducing school absenteeism due to asthma.

An elementary school, middle school, and high school were selected for the program to ensure cross-sectional impact. Based on comparatively high asthma rates and Integrated Pest Management (IPM) Indexes (total average percent of clutter, sanitation, and sign of overall pest activity), the following three schools were chosen for this pilot program: Boston Teachers Union, Mission Hill School and Excel High School.

The Consulting Team first researched and reviewed existing materials and other asthma intervention models to determine best practices in asthma management pertinent for program development. The team identified and met with

key collaborators and stakeholders in various fields of education, support, and advocacy in the Boston area, including representatives from BPS, Boston Children's Hospital, the Boston Public Health Commission, the Massachusetts Coalition for Occupational Health and Safety, Health Resource in Action, as well as other school administrators. As a result of these meetings, strong partnerships were formed and the methodology for the program was drafted.

The Consulting Team began with a walk-through at each of the three schools, generally conducted with the lead custodian, in order to understand the baseline data, which revealed visible mildew, old carpeting, indoor air quality issues, and food and trash outside of the cafeteria and on school grounds. Based on the Team's observations, original, written materials were produced, such as slide decks, fact sheets, and environmental checklists, all of which were translated into Spanish. The program design and materials were tested via focus groups, and then program components were revised, as needed.

The Be Smart and Breathe Easy Asthma Program was implemented in the three selected schools with the school nurses and custodial staff, beginning in October and ending in December, 2018. Common themes that emerged in the process included: the need for accurate asthma rates in BPS; more strategic Asthma Action Plan implementation; improved classroom tracking of children with most asthma symptoms in relation to environmental triggers present; remediation of environmental triggers; and the need to evaluate the HVAC systems, many of which are old.

AAFA New England was pleased to donate educational materials, nebulizers and tubing, spacers, EpiPen cases, and food allergy wristbands.

Conclusions and Recommendations:

The Consulting Team found that AAFA New England's Be Smart and Breathe Easy Asthma Program resulted in many positive outcomes in the schools, including:

- An increased knowledge about asthma and the environment among the nurses, nurse interns, custodians, and school leadership. Custodians and school nurses indicated that the asthma slide presentation was very useful, and suggested it would be a good refresher to present at their yearly professional development workshop.
- The school nurses' recommendation that it would be beneficial for AAFA New England to provide asthma education for the students' parents.
- Small environmental changes made by the custodial staff that were in their control, that will positively impact asthma outcomes, such as an uptake in the use of spray bottles with green cleaners and walk off mats.
- The recognition of the importance of consistent, ongoing feedback and education for school staff and faculty.



AAFA New England thanks Sanofi Genzyme for their generous grant to fund our Be Smart and Breathe Easy Asthma Program.

Copies of the Be Smart and Breathe Easy Asthma Program Final Report are available from AAFA New England upon request.

Jan Hanson, MA, is Board President of AAFA New England, and founded Educating For Food Allergies, LLC in 2001 where she specializes in school food allergy management. Jan is nationally recognized as a food allergy educator, author, speaker, and advocate.

RESEARCH UPDATE: OPPORTUNITIES TO HELP

ASTHMA PREVENTION STUDIES AT BOSTON CHILDREN'S HOSPITAL



Boston Children's Hospital

Until every child is well™

The Asthma/Allergy Clinical Research Center is an NIH funded

Center currently recruiting for a number of studies for patients with asthma and/or allergies! All visits are compensated and all travel to and from the hospital is covered by the research group. The studies also provide free medications.

- **PARK (Preventing Asthma in High Risk Kids):** Park is a prevention study aimed at identifying whether 2 years of treatment with Xolair® (Anti-IgE) injections can prevent lasting asthma or reduce asthma severity in children ages 2-4 years with a history of wheezing, allergies, and family history. Xolair® (or Anti-IgE) has been safely established for decades to treat asthma in children and adults, but investigators want to study if early treatment could prevent or modify the disease. These children are at very high risk of developing lasting asthma and other allergic conditions. This treatment blocks IgE which is important in allergies and has been shown to provide anti-viral benefits against the common cold. We will also evaluate whether this treatment stops or modifies the allergic march, which includes eczema, food allergies and other allergic conditions.
- **ORBEX (ORal Bacterial Extract for the prevention of wheezing lower respiratory tract illness):** The goal of ORBEX is to find out if oral treatment with Broncho-Vaxom® for 2 years can prevent lower respiratory wheeze or asthma like symptoms in children ages 5-16 months who have eczema

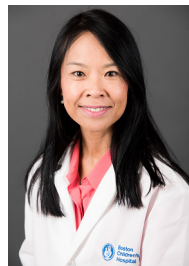
or who have a parent with asthma. The treatment is an oral treatment made of extracts of different kinds of bacteria responsible that has been established in Europe to treat children for common respiratory infections.

- **Vit-D Kids (Vitamin D to Prevent Severe Asthma Exacerbations):** The goal of the Vit-D Kids study is to see if taking a large daily dose of Vitamin D for one year can reduce the number of severe asthma exacerbations experienced by asthmatic children ages 6-17 years old. All asthma controller medication is provided to the family during the course of the study.

The Asthma Clinical Research Center also has a number of observational studies, including EASY (Environmental Assessment of Sleep in Youth) that is assessing the environment and providing home sleep monitoring, and evaluating the association between Activity Pediatric Outcomes in Children with Chronic Conditions, using a Fit-bit in school aged children. We are also working on a variety of novel therapeutics to treat bad asthma.

For more information about any of the above studies and/or for physicians to refer potential interested families, please email asthma@childrens.harvard.edu or call 857-218-5336.

Wanda Phipatanakul, MD, MS, is the Director of the Asthma/Allergy Clinical Research Center, Boston Children's Hospital, Professor of Pediatrics, Harvard Medical School



FOOD ALLERGY STUDIES AT MASS GENERAL HOSPITAL



"Outcome of Early Allergen Introduction," (abbreviation LEAP-IT) sponsored by the Broad Institute. The primary goal of the study is to

evaluate the success of introducing foods regarded as common allergens. The main eligibility criteria include: Age greater than or equal to 4 months and less than 4 years old, and a referral by a Massachusetts General Hospital allergist for food challenge as part of routine clinical care due to medical judgment of increased risk of allergy.

Wayne Shreffler, MD, PhD, is division chief of Pediatric Allergy & Immunology at MassGeneral Hospital (MGH) for Children and director of the Food Allergy Center at MGH.



RISING ASTHMA RATES

Asthma rates in the United States have been increasing over the last few years, and according to the Centers For Disease Control, 1 in 13 people have asthma. Boston, in fact, has one of the highest asthma rates in the country. Asthma prevention is imperative, and is extremely cost-effective as compared to the cost of acute medical treatment in a hospital emergency department. Most importantly, asthma education and asthma trigger remediation will serve to benefit the overall health and well-being of all individuals with this chronic health condition.

THANK YOU TO OUR CORPORATE PARTNERS

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

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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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
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- ☐ Practice Group \$250

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AAFA New England ANNOUNCEMENTS



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Maxwell & Eleanor Blum Patient
and Family Learning Center
White Building
First Floor, Room 110
55 Fruit Street
Boston, MA 02114
For more information, call:
617-724-7352 or email:
pflc@partners.org



Speaker Series

To register for the speaker
series, call AAFA New England
at 781-444-7778 or email us at
events@aafane.org.

Laurel Francouer
Attorney, Francoeur Law
"Flying with Food Allergies:
Planning Summer Travel"
Wednesday, April 24, 2019
7:00 - 8:00 p.m.
Boston Children's at Lexington
482 Bedford St., Lexington, MA

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

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



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