Asthma Treatment Then and Now by Christopher H. Fanta, M.D.

For most people asthma can be kept under control most of the time with modern medications. For persons with more active asthma, good asthma control may require taking a medication once or twice daily. Even the most difficult, refractory asthma can now usually be tamed by new “biologic” medications injected once or twice a month.

This wasn’t always the case. Forty years ago, circumstances were very different. When an inhaled quick-acting bronchodilator like albuterol did not provide adequate relief of symptoms, our typical advice back then was: 1) take your albuterol 4 times a day, because its benefit only lasts approximately 4-6 hours; and 2) begin a long-acting bronchodilator, theophylline. Slow-release theophylline tablets or capsules could be taken once- or twice-daily, providing continuous benefit day and night. Sounds good, but there were major drawbacks. Theophylline could cause nausea, vomiting, diarrhea, headache, and tremors; the correct dose varied from person to person, necessitating frequent check of theophylline levels in the blood; many medications would interact with theophylline, requiring dose adjustments; and theophylline overdoses could lead to potentially life-threatening heart irregularities and seizures. Most distressing was that, despite our best efforts at treating asthma, the number of asthma attacks, hospitalizations, and deaths from asthma continued to increase in the United States year after year.

Then, scientific research made a crucial discovery about asthma: besides spasm of the airway muscles causing narrowing of the breathing tubes, a key component of asthma was found to be inflammation of the bronchial tubes – a characteristic, allergic-type inflammation that is present all the time, even when one has no symptoms. Treatment of that inflammation is best achieved with anti-inflammatory steroids, which, if inhaled onto the bronchial tubes, have very few side effects. This discovery ushered in the widespread use of inhaled steroids to treat asthma. At first, they were given in small doses and recommended for use four times a day. With time, larger and more effective doses of medication were delivered in each puff, and twice-daily administration became the norm. Now some inhaled steroids can be taken effectively just once daily.

A second breakthrough occurred in the mid-1990s, when inhaled bronchodilators (like albuterol) were created that would have a beneficial effect not just for 4-6 hours but for 12 hours. They provided all of the long-acting bronchodilator benefit of theophylline with far fewer side effects and no need for blood testing. Used alone (without an anti-inflammatory steroid), these long-acting inhaled bronchodilators were associated with rare but dangerous asthma attacks; but used together with an inhaled steroid, they proved enormously effective in controlling asthma without an associated increased risk of attacks. Inhalers combining both types of medication quickly became available, so that with one or two breaths in, one can now inhale an anti-inflammatory steroid and a long-acting bronchodilator that together provide asthma control day and night. These combination inhalers are available for once- or twice daily administration.

Along with new medications came new delivery systems. Forty years ago we had primarily pressurized canisters (“metered-dose inhalers”) driven by atmosphere-polluting chlorofluorocarbons (CFCs). We now have environmentally friendly metered-dose inhalers (with HFA propellants) along with a variety of dry-powder inhalers, where medication is released with the force of one’s breath in. And all devices have a built-in dose counter. No longer are we asked to float the metal canister from our inhaler in a tub of water to see if it sinks or bobs on the surface as a means of estimating how many doses are left!

And best of all, our new treatments are working. Ever since the early 1990s, when use of inhaled steroids came to be promoted as first-line therapy for persistent asthma, the number of hospitalizations and deaths from asthma has steadily declined in the United States.

That said, it must be admitted that (continued on page 3)
2019 AAFA New England
BOARD OF DIRECTORS
Jan Hanson, MA, President
Suzanne Ginouves, Vice President
Tara McCarthy, RD, Clerk
Lyndsay King, CPA, Treasurer
Lisa Bartnikas, MD
Jennifer LeBovidge, MD
Margee Louisas, MD, MPH
Judi McAuliffe, RN
Giuliana Peguri, RN
Robert Stoker
Elizabeth TePas, MD
Mark Uzzell

MEDICAL ADVISORY COMMITTEE
Jennifer LeBovidge, PhD, Chair
Lisa Bartnikas, MD
Michael Pistiner, MD
Susan A. Rudders, MD
Elizabeth TePas, MD

HONORARY DIRECTORS
Irving Bailit, MD
Bette Barbadoro
George Behrakis
Cynthia Daley
Joseph Ferney
Hon. Gordon Martin, Jr.
Frank J. Twarog, MD, PhD

FOUNDING PRESIDENT
Albert L. Sheffer, MD
(1929-2015)

EXECUTIVE DIRECTOR
David Guydan

FROM THE EXECUTIVE DIRECTOR

Dear Readers,

This year, AAFA New England is celebrating its 40th Anniversary. In this edition of the Asthma & Allergy Bulletin, we will recount the history, provide updates on our current initiatives, and offer a glimpse into the promising future of our organization.

Join us for our 2nd annual “for life without limits” Fall Gala 2019 on Friday, October 25th, from 6:00 to 9:30 p.m. at the Boston College Club, downtown Boston. On Saturday, October 26th, we hope you will also attend our Family Concert and Food Allergy Expo, featuring Gala Honoree Kyle Dine, international food allergy educator and musician. And attend our Speaker Series events, in person or via streaming video. AAFA New England is grateful to Thermo Fisher Scientific for sponsoring our Fall Speaker Series.

Since becoming Executive Director just over a year ago, I have been privileged to learn about AAFA New England’s remarkable history. It is humbling to be part of adding to that history by the work we do every day in support of our asthma and allergy advocates. In honor of our past, present and with an eye on a bright future, I wish to dedicate this space to all of those who have made a difference for the asthma and allergy community.

History: AAFA New England was founded forty years ago through the leadership of Dr. Albert Sheffer, a pre-eminent Boston allergist, who organized a group of colleagues and patients to provide education, advocacy and support for research by forming a regional chapter of the national Asthma and Allergy Foundation of America. During the four decades since its founding, AAFA New England has sponsored hundreds of educational support group meetings and speakers, published a steady stream of informative newsletter articles, and responded to thousands of telephone and email requests for assistance.

From its early days, we worked closely with the Massachusetts School Nurse Association to advocate for a registered nurse in every school and with the Environmental Protection Agency to advocate for improved indoor air quality. AAFA New England was a participant in the successful “Make Smoking History in Massachusetts” campaign and raising awareness about the impact of “second-hand smoke.”

“Creating the Asthma-Friendly Child Care Checklist is among my proudest accomplishments,” said Sharon Schumack, who served as health educator and AAFA New England’s Director of Education and Programs for over twenty years. The checklist, including translations into Spanish, Portuguese and Haitian Creole, was developed as part of AAFA New England’s Asthma and Allergy Essentials for Child Care Providers training program. It was adopted for use nationwide and was reproduced by various state asthma programs. AAFA New England has worked with volunteer activists, school nurses, allergists and others to promote policies designed to help students with asthma and allergies be safe at school, in child-care, and at summer camps.

Present: We continue to expand our tradition of education and support, advocacy, awareness, and support for research.

• Education and Support: Introduced in 2017, our Speaker Series features topics of interest, such as Flying with Food Allergies, Asthma Basics, Hidden Allergens, Digital Health, and Living with Allergic Disease. These talks are now streamed “live” and available on our website! We went to Boston inner-city schools to deliver our Be Smart and Breathe Easy Program thanks to a generous grant from Sanofi Genzyme, which for the first time combined environmental assessments and remedial steps with asthma management treatment to improve the outcomes of students with asthma. Resources in English and Spanish were created and distributed through the schools and are available on our website. We look forward to launching SAGE support groups (Support-Advocacy-Group Education). Laurel Francoeur, one of the SAGE co-leaders said, “We are excited by the positive response to establishing local groups where parents and caregivers can “meetup” for support, share valuable information and gain greater understanding of asthma and allergies.”

• Advocacy: We advocate for public policies to improve the lives of people with asthma and allergies. Examples include Massachusetts bill S.255 (An Act to Establish Food Allergy Plans), S.1226 (An Act to Improve Food Allergy Awareness), and S.1276 (An Act Ensuring Safe Patient Access to Emergency Care).

• Awareness: We publish our Asthma and Allergy Bulletin three times per year thanks to a grant from The Thoracic Foundation. The Bulletin has original articles of interest and other features to inform our readers of events and new studies. AAFA New England is on social media, attracting an ever-widening network of people who share our posts and add their own experiences.

(continued on page 3)
Executive Director

David Guydan

And thank you to our asthma and allergy community for your encouragement and support,history and working hard each day to help people with asthma and allergy in managing their conditions “for life without limits™.”

The work of AAFA New England has never been more important and has never been more urgent. AAFA New England is proud of its history and working hard each day to help people with asthma and allergy in managing their conditions “for life without limits™.”

And thank you to our asthma and allergy community for your encouragement and support,

David Guydan
Executive Director
**AAFA New England: NEWS AND NOTES**

### Speaker Series Recap

“Asthma Basics” was presented on May 28th by Beth Klements, MS, PPCNP-BC, AE-C, Asthma Clinical Specialist at Boston Children’s Hospital. Beth provided valuable information on when to pay close attention and when to start to worry in the care and treatment of asthma. The session was streamed live and is available on the AAFA New England website for viewing on demand.

"Digital Health and Patient Engagement” was the topic on June 19th, when Joyhsna Mehta, Founder, Keva Health, was joined by Dhrumil Shah, MD, Chief Medical Information Officer at Compass Medical, in a spirited panel discussion on how big data and new apps are impacting monitoring and support of asthma and allergy patients. Also find the event on our website for on demand viewing.

### Helping a Family with Asthma

In July, the AAFA New England office received a phone call from a social service agency in central Massachusetts, asking if we might help a family in desperate need of an air purifier but unable to afford one. Their physician recommended an air purifier for the family of asthmatics who live in an apartment above smokers. The second-hand smoke from below was causing great stress especially to the children. AAFA New England, with the help of our national organization, was able to arrange the delivery of a Rabbit Air HEPA Air Purifier which was delivered in August. The agency reported that this was the "nicest gift the family ever received." Our thanks to Rabbit Air and to all who worked to make this possible.

### MSIC Charity Golf Tournament August 26, 2019

Thank you to our corporate sponsor, MSIC, for planning and hosting its Charity Golf Tournament at Black Rock Country Club on August 26th to benefit AAFA New England. We are so grateful for the leadership of MSIC and the generous support of the credit union community. Golfers hit the links in the afternoon, followed by a celebratory dinner – a terrific way to end a fine summer's day. This event raised almost $50,000 to support AAFA New England's important work, for which we are sincerely grateful.

### A HISTORY OF ADVOCACY

**Perspectives on Public Policy**

by David E. Newman

AAFA New England has played an important advocacy role in numerous public policy initiatives over the years. As a consultant to several coalitions, I’ve had the opportunity to work with AAFA New England on anti-tobacco campaigns and public policies that impact access to medicine and innovation. As AAFA New England celebrates its 40th anniversary, it is worth reflecting on a few prominent public health victories in which the organization played a vital role.

For over 20 years AAFA New England has partnered with Tobacco-Free Massachusetts, a coalition of health groups, and has been at the forefront of significant anti-smoking campaigns, helping by its advocacy to achieve lower smoking rates through regular excise tax increases, support for the state’s investment in tobacco control programs, and the creation of 100% smoke-free workplaces. We now take smoke-free bars and restaurants for granted, but securing clean air in these establishments was a real battle when first proposed 15 years ago. I’ll never forget the bartender who spoke up publicly at hearings and with reporters telling stories about the effects that secondhand smoke had on her and her co-workers’ health.

Today, the smoking issue has shifted into the vaping phenomenon that has a real grip on students. AAFA New England is mobilizing for advocacy to impact public policies that will stem the availability and use of e-cigarettes and vaping products and developing programs with compelling messages directed to students as early as middle school.

When it comes to research, clinical trials and access to therapies, AAFA New England has participated with like-minded organizations and agencies who all recognize the value of medicine in the Commonwealth. When aligned on an issue, groups speak up in support of or raise concerns over policies that could impact innovation. By hearing personal stories and patient perspectives on key issues, decision-makers gain a broader view of how policies might affect their constituents.

By developing a diverse grassroots network, AAFA New England is strengthening its capacity to support key legislative goals related to asthma and allergies in the years ahead. This strategy, through hard work, will yield a great return in the future. Consider getting involved as an advocate for improved asthma outcomes. Share your personal health story with your elected officials and the media as part of a public policy campaign. Join a local AAFA New England SAGE support group this Fall as a great way to get involved in advocacy while gaining support for your own asthma and allergy concerns.

Dave Newman is Executive Vice President and a consultant at The Strategy Group, which provides public affairs, media and community relations support to corporations, associations and nonprofit organizations.
Many chocolate companies manufacture products that contain or may contain nuts. For a nut allergic child, chocolate was not a childhood indulgence. Tanner, a little boy with peanut allergy, was unable to find for his peanut and tree nut allergy. Not wanting Tanner to miss out on a classic childhood indulgence, Gail began making her own homemade chocolate that was 100% guaranteed peanut and tree nut free. Vermont Nut Free Chocolates was the first company to enter into the peanut free and tree nut free space. As soon as the website was launched, customers from all around the country started purchasing their safe and delicious products. The company grew organically through word of mouth and these early adopters quickly became raving fans.

Growing up with multiple food allergies, Kyle experienced first-hand the challenges that food allergies play during adolescence. After experiencing a harrowing anaphylactic reaction in his early twenties, he changed his career path in order to create tools and resources to help people avoid allergic reactions and improve overall quality of life.

Dr. Christopher Fanta grew up in Brooklyn, New York, the second son of a general practitioner, Eugene Fanta, who later in his career became a family practitioner and founded the first Family Practice residency training program in New York City. Chris attended Harvard College and then Harvard Medical School and then began his internship and residency training in Medicine at what was then the Peter Bent Brigham Hospital. He was drawn to Pulmonary Medicine by his early mentors, including Drs. Roland Ingram and Regis McFadden, giants in the study of asthma physiology.

During his fellowship training in Pulmonary and Critical Care Medicine, he engaged in asthma research projects, including studies of the mechanism by which exercise provokes airway narrowing in persons with asthma, and randomized trials exploring the best treatment options for persons suffering acute asthma attacks.

He then joined the faculty of of the Division of Pulmonary and Critical Care Medicine at Brigham and Women's Hospital, and he has remained there ever since. Although he stayed engaged in asthma research, his greatest passion in medicine has always been the direct care of patients. In 1989 he helped create an Asthma Center focused on patient care and asthma education, which notably included both allergists and pulmonologists collaborating together. This Asthma Center morphed into the Partners Asthma Center, and grew to include allergists and pulmonologists at Faulkner Hospital, Newton-Wellesley Hospital, and North Shore Medical Center, now too with affiliates at Harbor Medical Associates and Pentucket Medical. Dr. Fanta is Director of Partners Asthma Center, which celebrates its 30th Anniversary this year.

Kyle Dine is a food allergic individual who has turned his diagnosis into several positive impacts for the food allergy community. He is a trusted food allergy educator and musician who performs engaging allergy awareness assemblies in elementary schools across North America. Along with his “Kyle Dine & Friends” DVD, which was funded through the allergy community on Kickstarter, his music and live assemblies contain empowering, supportive, and educational messages for children with or without food allergies.

His educational efforts guided him to project work with Food Allergy Canada on their programs, resources and advocacy. Since 2008, he has specialized in the development of materials for youth and led projects such as elementary and high school awareness programs, educational books, videos, and the Allergy Pals online mentorship program.

An avid traveller, Kyle founded www.allergylanguage.com in 2006 to help people travel with allergies by providing cards with professional translations of allergens in foreign languages. He earned a master's degree in 2019 at Queen's University for innovation management and entrepreneurship, and is currently relaunching his allergy travel resources under the new name Equal Eats. His goal is to help people with dietary restrictions enjoy food safely all around the world.

**Vermont Nut Free Chocolates** was founded in 1998 by the mother of a little boy with a potentially life-threatening peanut allergy. Gail and Mark Blyde first learned of their son Tanner’s allergy when he suffered a reaction at 8 months old. To ensure their son’s safety, they began to thoroughly read ingredient labels and discovered that the hardest product to find for a nut allergic child was chocolate. Many chocolate companies manufacture products that contain or may contain nuts and demanded that retailers carry the brand. Wholesale and distribution channels have continued to expand over the years along with direct to consumer sales. Vermont Nut Free Chocolates now has over 30 devoted employees and is committed to providing quality chocolates and treats that are fun, safe and delicious for those with peanut and tree nut allergies. From chocolate covered pretzels and gourmet truffles to granola bars and trail mix, those with and without nut allergies will find their gourmet chocolates to be among the finest they have ever tasted. In addition to ordering online, customers can now find their products in over 500 stores nationwide.
RESEARCH UPDATE: OPPORTUNITIES TO HELP

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. Call or email to see if you or your child is eligible for any of these exciting studies!

- **PARK** (Preventing Asthma in High Risk Kids): Park is a prevention study aimed at identifying whether 2 years of treatment with Xolair® (Antigen) injections can prevent lasting asthma or reduce asthma severity in children ages 2-4 years with a history of wheezing, allergies, and family history. 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.

- **IDEA** (Investigating Dupilumab's Effect on Asthma by genotype)
- **PRECISE**: We are investigating whether novel therapies can help asthma in adolescents and adults
- **EASY** (Environmental Assessment of Sleep in Youth): Study of home environmental factors (noise, air quality, etc) in the child's home to modify the quality of the sleep. This study is for children ages 6-12 years old.

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

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

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

Oral Encapsulated Fecal Microbiota Transplantation in Peanut Allergic Patients

The Boston Children's Hospital Allergy & Immunology Division is conducting a research study to help determine if Fecal Microbiota Transplantation (FMT) is useful and safe in treating peanut allergies. This study uses FMT in the form of oral, frozen, tasteless and odorless capsules containing stool from healthy, non-peanut allergic donors. The study is led by Dr. Rima Rachid. We are recruiting peanut allergic adults aged 18-40 years. Participants may also be allergic to tree nuts, but no other foods. The study lasts 4 months, with 8-10 visits and an optional follow up visit at 1 year. Compensation is provided and a travel reimbursement may be available. For more information, please call the study coordinator at (857)218-5331 or FMTpeanutstudy@childrens.harvard.edu.

LEGISLATIVE ADVOCACY

Support of S.255: An Act to Establish Food Allergy Plans, June 3, 2019

MA State House Joint Education Committee Hearing on S255. Jan Hanson, AAFA New England Board President, represented AAFA New England constituencies, and spoke about the importance of a plan for each school in MA, with staff ready and trained to respond to emergencies, and for access to epinephrine. Dr. Mike Pistiner organized a wide contingent of support for the pending bill.

Meeting at Representative Katherine Clark's (D-MA) office with Jay Higgins, Healthcare Advisor to Rep. Clark, August 15, 2019

David Guydan attended with Erin Hearn, Alliance Development Coordinator at J Strategies and Nicole Arpiarian, AAFA New England supporter and food allergy advocate. Discussion topics included transparency in drug pricing, affordability through imposition of out-of-pocket caps, and creating incentives for greater accessibility of prescription drugs.

Briefing on the Road to Lower Drug Costs organized by We Work for Health June 19, 2019

The discussion was well attended by healthcare providers and other interested parties to walk through impending changes to Medicare and explore beneficial proposals designed to reduce patients’ out-of-pocket costs at the pharmacy.
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. ©2019. All rights reserved. Material may not be reproduced without permission of the publisher.

BECOME A MEMBER OR RENEW YOUR MEMBERSHIP!

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

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

MEMBERSHIP INCLUDES

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

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

MAKE A DONATION TO AAFA NEW ENGLAND

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

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

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

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

Honor an Individual or Organization

Purchase a tribute for our Fall Gala 2019 Program Book to help celebrate our 40th anniversary. Send us your tribute for AAFA New England and our work as an organization, or for individuals affiliated with AAFA New England – the Board, the Medical Advisory Committee, staff – for their dedicated support of the asthma and allergy community. You choose! Go to asthmaandallergies.org to make your tribute.
AAFA New England ANOUNCEMENTS

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

Fall 2019 Series sponsored by: ThermoFisher Scientific

"Living with Allergic Disease: The Role of Specific IgE" Tuesday, October 8, 2019, 7:00 – 8:00 p.m., AAFA New England Office, 25 Braintree Hill Office Park, Suite 200, Braintree, MA.

Presenter: Lakiesha Wright, MD, MAT, MPH, US Medical Director of Clinical Affairs, Immuno Diagnostics, Thermo Fisher Scientific and Associate Physician, Brigham and Women’s Hospital, Harvard Medical School

"Hidden Allergens: What You Need To Know," Thursday, November 21, 2019, 7:00 – 8:00 p.m., Newton-Wellesley Hospital, Bowles Conference Center, Shiplay Auditorium, 14 Washington St, Newton, MA (UAB West Entrance)

Presenter: C. Giovanni Traverso, MD, BChir, PhD, Division of Gastroenterology at the Brigham and Department of Mechanical Engineering at MIT.

Dr. Traverso will be joined by a representative from CVS/Pharmacy for a panel discussing a new study of hidden allergens in medications and common products including beauty products, soaps, over-the-counter remedies, vitamins, liquid medicines, etc.

Speaker Series sponsored by:

SAGE (Support-Advocacy-Group Education) Program

AAFA New England is forming support groups centered on five locations:

- Northwest Boston (Lexington)
- Metrowest – Boston (Newton, Wellesley and nearby communities)
- South Shore – Boston (Weymouth and surrounding communities)
- Springfield
- Providence, RI

Each SAGE will have co-leaders, a Medical Advisor, and members who “meetup” for support and education on asthma and allergy conditions. Access to Speaker Series events, resources and materials of AAFA New England, and facilitated and ad hoc discussion groups make SAGE the place to be! Contact the AAFANE office at 781-444-7778 to join or email us at sage@aafane.org.