ASTHMA & ALLERGY

ASTHMA AND ALLERGY FOUNDATION OF AMERICA • NEW ENGLAND CHAPTER

Debbie Saryan is new AAFA New England Executive Director



Debbie Saryan of Andover, MA has been appointed Executive Director of the Asthma and Allergy Foundation of America, New England Chapter.

"As a longtime volunteer and somebody that has benefited immensely from the resources of the organization, I'm looking forward to this new role as an opportunity to give back," she said.

Debbie knows first hand what it's like to have life-threatening allergies, and is also well-acquainted with the asthma and allergy community through attending medical conferences and programs with her husband, allergist John Saryan, MD. "Through my contact with professionals in the field I've gained some insight on what's important in treating asthma and allergies, and how AAFA New England can provide support to physicians and patients."

Debbie is a former research librarian, an experienced grant writer, and has been a member of the board of directors of various other non-profit organizations. She has served as chair, co-chair or committee member of AAFA New England's Breath of Spring annual fundraiser for many years.

"We're delighted to have Debbie's energy and enthusiasm at work for our organization," said Dr. Frank Twarog, President of AAFA New England.

RESEARCH UPDATE

Peanut allergy ... And the beat goes on!

By Frank J. Twarog, MD, PhD

Researchers around the world continue to learn more about peanut allergy, a major cause of life-threatening food reactions. Here are some highlights of studies that are adding to our knowledge of when and why the allergy begins and what can be done to prevent severe reactions.

In this newsletter
we have previously
discussed a theory,
suggested by a British
study, that contact
through the skin may
be a cause of children
becoming "sensitized" to
peanut – the immunological process
that leads to allergic reactions.

More recently, an interesting observation from Hong Kong suggests that early exposure to low doses of peanuts may induce tolerance – making an allergic reaction less likely. According to this observation, when crude peanut oil

containing significant amounts of peanut protein was commonly used, the frequency of peanut allergy in Hong Kong was quite low. Olive oil has largely replaced peanut oil, and since then there has been an increased incidence of peanut allergy there. This is consistent with observations made in several other studies.

Unfortunately, as a study of more than 1,400 peanut-allergic children in Canada indicates, *inadvertent* exposure continues to occur. In the five-year study, the annual rate of reactions in allergic children was 12.5%. Surprisingly, 39.5% of these reactions occurred in the children's own home and an additional 6.4% in schools. Of these schools, 71% were supposedly peanut free! Even in children who had a history of mild reactions in the past, some of the inadvertent exposures resulted in severe anaphylaxis.

(Continued on page 2)

Does your asthma get worse at work?

When we asked people to come up with poems about the work of our organization, occupational asthma specialist Elise Pechter sent us this lighthearted verse that highlights a serious problem: the many adults who are affected by asthma triggers they encounter in their workplace.

Be sure to let your doctor know about fumes, air particles, or other worker's pets or perfume that could be affecting your asthma. Asthma issues don't disappear when you're grown
Our attention to detection and prevention must be sown
Asthma in adults is 70 percent of all
Yet efforts to protect are frequently stalled
We need to ensure adults are symptom-free
And ask about life, even feelings and sleep
At work, what can we do to prevent?
Conditions can change—a message that must be sent
Efforts to prevent asthma—not an isolated quirk
As we integrate attention to home, school and work

RESEARCH UPDATE (continued from page 1)

Not surprisingly, in view of this type of data, researchers continue to try to prevent serious reactions by inducing tolerance in children who are already sensitized. In a study conducted in England, investigators found that, in a small population of 22 children (mean age 11 years), a very slow carefully controlled introduction of peanut over a period of eight to 38 weeks, provided protection for the equivalent of the ingestion of five peanuts. The

average tolerance increased by 1,000-fold following the oral immunotherapy. No serious adverse events occurred during this immunotherapy.

This study, together with a number of others over the last several years, supports the use of oral desensitization under careful observation as at least one means of minimizing severe reactions due to inadvertent exposure.

Eating Out is Complicated

At the present time, however, the reality is that the vast majority of individuals with peanut allergy have not been treated. This certainly poses a problem for those who wish to eat out. The practical approach to dealing with this challenge was investigated by researchers who interviewed 32 adults with sensitivity to peanut or tree nuts.

The results of this questionnaire provide some insight into dining experiences and concerns expressed by this group. The authors point out that the "social implications" of discussing their allergy with wait staff sometimes made these people feel they were viewed as "simply being fussy or picky about what they ate." The participants also expressed concern that many wait staff may simply answer their inquiries casually or incorrectly. On the other hand, if some of the wait staff are overly conservative, they may provide more stringent or restrictive interpretations, limiting even further the foods the allergic individuals would be comfortable eating.

Since approximately 25% of reactions occur while dining at restaurants, eating out is itself considered high risk. Nut-allergic people generally approach their problem in a pragmatic and sensible fashion. Because of cross contamination or unexpected ingredients, most participants labeled certain cuisines as "high risk." These include a variety of Asian, Chinese and Mexican cuisines, and therefore participants avoided these restaurants.

Traveling with food allergies?



Communicating with restaurant staff is the key to staying safe. Check our website (www. asthmaandallergies.org) for a list of resources for translating the names of your food allergens into various languages,

identifying possible sources of allergens in international cuisines, and tips for eating out with food allergies.

Some of the participants in the study related a sense of regret that they are unable to spontaneously choose their restaurants or the food they could order. The authors correctly noted that this was one of the first studies done from the perspective of adults rather than children or adolescents with nut and peanut allergy, on whom most of the literature has been focused.

Another important factor reported by this study is the possibility that language barriers in some restaurants, as well as poor understanding of allergy by the wait staff, may be a further problem. The authors noted that education of individuals with food allergy as well as restaurant staff is essential to minimize the risks. They close by stating, "We have seen, however, that from the patient perspective, some of these patterns are grounded in legitimate, everyday social considerations around embarrassment, choice, and spontaneity. Education and training strategies are needed to recognize and take account of this."

Does everyone know what peanuts and tree nuts actually look like?

Finally, it is of some interest that both children and adults are unable to correctly identify peanuts and tree nuts to minimize their risk of exposure. In a study from Ohio, investigators evaluated over 1,000 children and adults to test their ability to correctly identify peanuts or tree nuts. A display was prepared which contained peanuts and tree nuts presented in 19 different forms, both shelled and unshelled. Participants were asked, after observing this display, to identify the foods. Only 50% of all participants in this study who had peanut or tree nut allergy were able to correctly identify all forms of peanut or tree nuts to which they were known to be allergic! Parents of children with peanut or tree nut allergy did no better than parents of children without allergy. Clearly, being unable to identify a food to which someone is allergic places them at increased risk of inadvertent exposure and reactions.

Sources:

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Frank J. Twarog, M.D., Ph.D., is an allergist in Brookline and Concord, MA, and serves as President of the Asthma and Allergy Foundation of America, New England Chapter. He is a Clinical Professor at Harvard Medical School.

FROM THE BOOKSHELF

Share the Trials and Triumphs of a Food Allergy Family

THE TRIALS AND TRIUMPHS OF

Feeding EDEN

SUSAN WEISSMAN

Feeding Eden
The Trials and Triumphs of a
Food Allergy Family
By Susan Weissman
Sterling Publishing - 2012

Reviewed by Rose Ann Miller

I am almost nervous to review Susan

Weissman's Feeding Eden because I worry that I will not be able to fully and accurately express just how good, how helpful, and how meaningful this book has been to me.

When my five-year-old son was diagnosed with severe food allergies at 18 months of age, I felt completely untethered. It's scary enough to bring up a child in this

world. What with diapers, feeding schedules, booster shots, and teething all parents have their hands full. But then, to discover that your child has not just an allergy but also a life-threatening allergy made me feel vulnerable and alone. And the truly scary thing is that this reaction—one that mimics having the wind knocked out of one's chest—is natural. How can a mother encourage her child to grow and explore the world when that world, the one that lies just beyond the window, is toxic to him in so many ways?

My perspective and my feelings changed once I read Weissman's tour de force Feeding Eden. Not only is the book well written and engaging, but Weissman speaks to parents and caregivers of food allergic children. And she speaks to us as a friend. You get the sense that you and the author are sitting cozily, side-by-side on the sofa while she relays her journey through food allergies with her son, Eden. The author really lets you into her world; each story is intimate and revealing. In fact, Weissman was so

forthcoming and so open about her feelings that I almost wanted to lean over and say, "wait, let me share my story too."

Weisman's story begins when Eden is just a baby and has horrible eczema. Actually horrible is a misnomer. Eden's eczema is

nightmarish. He also has trouble eating, sleeping, he cries a lot, is clingy... the list goes on. Feeding Eden chronicles Weissman's journey to find the right pediatrician and allergist for her son. She has a lot of trial and error until she finds a correct diagnosis for Eden and the right doctors for him.

While Weissman finds the right doctor, she explores and relays the medical side of food allergies, but in a way that's easy to understand. She also takes us inside her family's kitchen, sharing her knowledge about recipes and how to navigate holiday gatherings, birthday parties, and school celebrations. Reader: I cried at Weissman's stories. The day-to-day situations that Weissman describes are so real to the parent of a food allergic child that I wept with joy that there was someone out there who understood my heartache for my son and his situation.

Weissman has a loving husband, as do I, and another child without food allergies—me too. She relates how her family has reached a stasis when it comes to food. Everyone may have a sandwich for dinner, she says, but not everyone's sandwich will look the same. When it was time to make a birthday cake for Eden, Weissman relentlessly and tirelessly makes cake after cake until, finally, she finds one that's right.

Throughout Feeding Eden Weissman is confessional—even delving into dark places. She bravely admits (something I've thought plenty but never had the guts to speak aloud) that she almost feels calmer when Eden has a reaction because she can actually do something. What she means is something that I've felt too: I worry. Every moment my son exists is a moment when he could, realistically, have a reaction. While he is not consciously aware of the risks at this age, I am. However when he is having a reaction (my son, like Eden, has had anaphylaxis a few times), the epinephrine has been used and he's been fine.

Weissman is neither hyperbolic nor belittling about Eden's situation and the day-to-day challenges. She tells it like it is. I cannot say enough good things about *Feeding Eden*. Actually, the only thing I didn't like about the book is that it had to end.

I encourage you to read *Feeding Eden*. I know you will benefit from Weissman's candid retelling of her own difficult story. To me, the book was a lifeline that I am still clinging to, still savoring and appreciating.

We have a copy for you!

Author Susan Weissman visited our Metro-Boston support group recently and shared stories from her terrific memoir Feeding Eden, a mother's story of how childhood food allergies affected the life of her son and her family.

Weissman donated some copies of her book to share with you. We still have a few copies available to send as "thank you" gifts for a \$100.00 donation to AAFA New England.

Breath of Spring 2013 Taste or Spring April 26, 2013

AAFA New England's annual fundraiser featured great food and spirits "tastings" and a fabulous silent auction.

We honored esteemed allergist Albert E. Sheffer, MD, our distinguished **Founding President, in sincere** appreciation of his foresight

and many years of dedication, support and commitment to our organization, and Massachusetts State Representative Jay Kaufman for his unwavering support and success in advocating for children with life-threatening allergies.



Debbie Saryan and honorees

Breath of Spring **Committee**

Debbie Saryan, Chair

Cindy Aswad Holli Bassin Cindy Blonder Michele Carrick Laurel Francoeur Jennifer Battelle Logan Patricia Pino Madelaine Stoker Robert Stoker Photos courtesy of

Carla Uzzell Mark Uzzell Anathea Waitekus











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Allergy & Asthma Associates South (Drs. Costa, Ghoshhajra & Ripple)

Allergy & Asthma Center of Massachusetts (Drs. Steinberg & Ohman)

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Debra & John Saryan, MD South Shore Allergy & Asthma

Specialists (Drs. Broff, Vallen & Young)

*Donations of \$500 or more. (See our website for a complete list.)

Our sincere thanks to the many others who purchased tickets to attend, or contributed donations or auction items.

AAFA New England

EDUCATIONAL SUPPORT PROGRAMS provide you with opportunities to

Learn from experts • Get your questions answered

Meet others who share your concerns
 Find resources and confidence

FOR MEETING DATES AND TOPICS:

see our website (www.asthmaandallergies.org) or call 781-444-7778.

METRO-BOSTON ALLERGY & ASTHMA SUPPORT GROUP Newton, MA

Meets at Newton-Wellesley Hospital, 2014 Washington St. (Rt. 16)

NORTHWEST SUBURBAN BOSTON AREA SUPPORT GROUP - Lexington, MA

Meets at Beth Israel and Children's Hospital Medical Care Center, 482 Bedford St.

FOOD ALLERGY GROUP OF THE NORTH SHORE Salem, MA

Meets at Salem Hospital, 81 Highland Ave. (Davenport Conference Area)

METRO-WEST ALLERGY & ASTHMA SUPPORT GROUP Framingham, MA

Meets at Allergy & Asthma Treatment Specialists, 475 Franklin St., Suite 206

PIONEER VALLEY FOOD ALLERGY SUPPORT Ludlow, MA

Meets at St. John the Baptist Pastoral Center, 201 Hubbard St.

SHORESIDE ASTHMA & ALLERGY EDUCATIONAL SUPPORT GROUP Kingston, MA

Meets at Wingate - The Inn at Silver Lake, 21 Chipman Way

CAPE COD ASTHMA & ALLERGY GROUP Yarmouth Port, MA

Meets at Allergy & Asthma Center for Cape Cod, 244 Willow St.

The following groups are currently temporarily inactive.

MÉRRIMÁCK VALLEY ASTHMA & ALLERGY SUPPORT GROUP

NASHOBA VALLEY ASTHMA & ALLERGY EDUCATIONAL SUPPORT GROUP

RHODE ISLAND ALLERGY & ASTHMA EDUCATIONAL SUPPORT GROUP

SOUTHEASTERN MASS. FOOD ALLERGY PARENT SUPPORT GROUP

Send your e-mail address if you would like to receive announcements about support group programs.
Let us know which group is closest to you. Send to: aafane@aafane.org

Songs about food allergies? You must be nuts!

Singer and songwriter Kyle Dine

performed his fabulous songs about staying safe with food allergies at a free family concert sponsored by AAFA New England this spring.

The gym of the West
Suburban YMCA in
Newton, MA was filled
with children dancing and singing
along as they learned important
information about label reading,
telling adults if they are experiencing
symptoms, always having epinephrine
on hand, and much, much more.

"For our daughters Kyle is like

a huge rock star," said Mark Uzzell, a member of the AAFA New England Board of Directors. "They have learned so much from his lyrics and his terrific attitude about having food allergies." Mark was instrumental in bringing Kyle to the Boston area, handled all arrangements for the concert,

and recruited fourteen sponsoring companies whose exhibits and samples were another highlight of the morning. We hope to make it an annual event! Sample Kyle's songs at his website: www.kyledine.com.

Make a difference through Workplace Giving

Help us to help YOU by earmarking donations through the charitable giving campaigns at your workplace.

If you donate to AAFANE directly, don't forget to ask about your employer's "matching gift" program.



SHARE YOUR STORY

"Allergy Shots" Helped Make Me a Champion

By Nicole Zais

Swimming is a minimalist sport in terms of equipment, though you do need a couple of things to practice. A suit, a cap, and a pair of goggles are the barest essentials required of a swimmer. Oh yeah, you also need your breath.

I learned to swim at a young age and I loved it, immediately jumping into the competitive aspect of the



sport as soon as I could, which would lead me to a successful career at the high school and collegiate level. I learned about allergies at a young age as well, accepting the sniffs, sneezing and stuffy noses as a part of my life.

In high school, one sport I tried was indoor lacrosse, which involved short intense games taking place in a

giant indoor warehouse...full of dust. This was when the asthma first appeared. Sports-induced asthma is often hard to explain to other athletes who want you to push yourself as hard as they are, so I would quietly take my inhaler and, like my allergies, I learned to live with it.

Crossing over into swimming, the asthma stayed, thriving, I felt, in the confined and chlorinated air of the pool. Nonetheless, I had a successful career in high school and decided to continue on with swimming at the Division III level at college.

Knowing that I would be in one place for the next four years, I began to see an allergist near my college. As I came to know Dr. Accetta and the great group of people working at Allergy & Asthma Care in Taunton, Massachusetts, I also came to understand my asthma and allergies more. I began treatment with "allergy shots" and noticed a steady improvement in my allergies. I was pleased with my progress, but the true test would come during the swimming season in my final year of college.

The Division III NCAA championship swim meet includes athletes from all Div. III schools nationwide who have made a certain cut time in order to compete at the national level. As I aimed for this goal I trained hard twice a week with a trainer in an enclosed and dusty space, and trained and competed in heavily fumed chlorine and bromine pools. In February of my senior year I became the first female athlete from Wheaton College to earn an "A" cut: a time that was fast enough to guarantee admittance to the meet and to seed me 5th in the nation in the 200-yard breaststroke.

I went on to train for another month and to succeed at the NCAA meet, coming in 6th in the 200-yard

breaststroke and 15th in the 100-yard breaststroke, each time improving my times and becoming the first female athlete from Wheaton swimming and diving to achieve individual All-American status.



Yet, all these accolades pale in comparison to what really happened: my true success story. I had achieved all of this in spite of my asthma and because of my allergy shots. I had effectively managed my handicap and navigated around it to the point where I was no longer using my inhaler three or four times a meet: I would only take one puff before warm-up and I could still breathe for the next three hours.

Whenever I go swimming now, I make sure to pack my suit, cap, goggles and inhaler, so I can take a deep breath and dive into the cool, clear water with a smile.

Please share YOUR story. How have you handled "real-life" challenges of living with allergies or asthma? Let us know what happened and how everything worked out.

(Send to: sharons@aafane.org or call 781-444-7778.)

Shopping?

Start your AMAZON.COM shopping from our website

When you do, a portion of what you spend will be donated to our organization at no extra cost to you! This is an easy way to help support asthma and food allergy education and advocacy.

Go to our home page (www.aasthmaandallergies.org) and look for the Amazon.com search box
Simply type in the "keyword" for the specific item or category of item that you are shopping for and then start shopping as normal.

Please bookmark this on your computer and share this information with family and friends.

Thanks, and happy shopping!

We help schools, child care providers and health professionals help YOU manage asthma!



AAFA NE Executive Director Debbie Saryan; Pioneer Valley Asthma Coalition leader Ann Ottalagana and guest speaker Maureen George

"Top notch information, excellently delivered" is only one of the glowing comments offered by participants at the "Asthma Management and Education" seminar we held this spring in Holyoke, Massachusetts.

Eighty nurses and respiratory therapists were treated to a presentation by nationally renowned lecturer Dr. Maureen George of the University of Pennsylvania Schoool of Nursing, on how to help patients keep asthma well controlled

The program was co-sponsored by AAFA, the Pioneeer Valley Asthma Coalition, and the Holyoke Food & Fitness Council.



Evelin Viero

"Asthma and Allergy Essentials for Child Care Providers" is the title of the workshop we offer to help keep children safe and healthy when they are cared for outside of their homes. Recent grants have enabled us to bring the program to Watertown, MA and to child care providers in 22 towns in the Boston Metro-West region.

With the addition of Evelin Viera to our faculty we are also now able to offer this program in Spanish. Evelin is a registered nurse, certified asthma educator, experienced trainer, and serves as health consultant to child care programs in the Lawrence, MA area.

School nurses: AAFA New England can provide you with spacers and peak flow meters for teaching purposes and for use by students whose families can't afford them. We also have teaching tools and activity books.

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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. ©2013. All rights reserved. Material may not be reproduced without permission of the publisher.

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Membership in AAFA New England helps you and others with asthma		
and allergies to □ Patron \$500 □ Benefactor \$250 □ Professional or Sponsor \$100 □ Renewal □	enjoy fuller lives. Sustaining \$50 Single/Family \$25	MEMBERSHIP INCLUDES ♦ Newsletters mailed to you (Multiple copies to Professional members) ♦ Personalized resources and information ♦ Notice of educational programs and special events • 10% discount on books
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Donations have recently been received in memory of:

Phillip Chapman

Paul Dashner

Leatrice Jacoby

Elizabeth Lane

Donations can also be made in honor of family, friends, or healthcare providers, or to mark special occasions.

To contribute a memorial gift or tribute in honor of a special person or a birthday or other event, please send a check payable to AAFA New England. MC/VISA accepted by phone, mail or on-line: www.asthmaandallergies.org. Please include the name of the person being honored or memorialized, and let us know who to notify of your donation.



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Did you pick up this newsletter in your doctor's office?

To receive future issues at home, become a member of AAFA New England. (See page 7)

AAFA celebrates 60 years



AAFA New England is proud to be a Chapter of the Asthma and Allergy Foundation of America, the largest and oldest asthma and allergy patient education organization in the world. AAFA's mission – research, advocacy and

education – has not changed since its founding in 1953, but the number of people living with these diseases has. An estimated 60 million Americans are living with asthma and/ or allergies today.

The New England Chapter, founded in 1978, provides educational programs and materials and customized assistance about asthma and allergies to individuals, schools, health and child care agencies, athletic and after school programs and workplaces throughout New England. AAFA New England sponsors educational support groups and training programs, publishes a newsletter and other educational materials, and runs a telephone information and referral service and speaker's bureau.

Become a member! Let us know how we can help you!

Save the date to GOLF for a good cause:

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Dr. Paul J. Hannaway
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Sept. 16, 2013
Tedesco Country Club Marblehead, MA

If you haven't participated in this tournament before be sure to let us know your address so we can send registration details.



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