a publication of the Asthma and Allergy Foundation of America, St. Louis Chapter



Asthma and Allergy Foundation of America, St. Louis Chapter • Fall/Winter 2016



Asthma and Allergy Foundation of America®

ST. LOUIS CHAPTER

#### **Upcoming Events**

Friday, September 23

USAnaphylaxis Summit (info inside)

#### Monday, September 26

**AAFA-STL Program Committee** Meeting @ AAFA-STL Office, 6:00-7:30pm

#### Saturday, October 1

Sathya Sai Health Fair @ Holy Trinity Church (St. Ann, MO), 9:00am-1:30pm

#### Thursday, October 20

AAFA-STL Board Meeting @ AAFA-STL Office, 6:00-7:30pm

#### Friday, October 21

Healthy & Sustainable Homes Initiative @ South County Health Center, 8:15-11:00am

#### Saturday, November 5

12th Annual Trivia Night @ JCC Staenberg Family Complex (Creve Coeur, MO), 7:00-10:00pm



This newsletter is made possible through support from Sanofi US

# A Message from Dur Executive Director

Dear Friends & Supporters,

Kids are back in school and our RESCUE program is "rocking"! Through a grant from Variety the Children's Charity, AAFA-STL is pleased to be serving 10 additional counties in Missouri by providing support with asthma equipment and medicine (we are sharing this distribution with our asthma partners in Springfield, MO). We also learned that 54% of all public schools in the state have implemented the RESCUE law for schools to stock albuterol for any child who may be experiencing an asthma emergency. We are so proud to be reaching further into areas of need throughout Missouri.

We are also glad to report that Missouri Care and Harmony of Illinois have contracted with us to provide their high-risk client families with asthma education, telephonic asthma coaching, and healthy home assessments. This begins in September. We are thrilled to have this opportunity with a managed care company, and this venture has lead us to become a Medicaid provider!

In other news, we have been vigilant in tracking recent news about the drastic price increase in EpiPen® devices. While the incidence of severe food allergies has risen, it has been extremely difficult to watch the price of epinephrine auto-injectors skyrocket. We have been raising awareness of the issue, due to our concern for families that are unable to afford this medication, and also to urge families to be knowledgeable of resources available. Please stay tuned to our e-newsletters and social media channels for updates on this important issue.

Speaking of epinephrine auto-injectors, the attempt to pass legislation in Missouri that would permit these life-saving devices in public venues did not pass, but our effort to increase public awareness of the severity of anaphylaxis has not waned. Therefore, we will be building on our AllerTrain™ program, to provide education to employees of restaurants, sporting venues, museums, etc. on what to do in the event of anaphylaxis due to food or other allergies. We are hopeful that the MO legislature will make this law a reality in 2017, as many states have already implemented it.

Our own Rising Leaders program continues to inspire us to increase our presence in the community - you can read more about this exciting new venture for AAFA-STL inside!

We are extremely grateful to each and every one of you who supports us in any way. We are a small team of seven, but mighty, nonetheless. Without you, we could not provide our services or programs. Thank you!

Joy B. Krieger, MA, RN **Executive Director** 

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Mission: The Asthma and Allergy Foundation of America, St. Louis Chapter serves those affected by asthma and allergies through education, support and resources.

#### **Mission Moment: Notes from a Client**





"I have had such a fruitful summer studying and interning abroad in Amman, Jordan. My study abroad group has traveled to Irbid, Petra, Wadi Rum, Karak Castle, Agaba, the Red Sea, and the Dead Sea. I am so grateful to AAFA-STL for providing me with all the medications I required to travel to and within this country. I have been able to swim in the Red and Dead Sea without fear of having an asthma attack while swimming. I have been able to climb ruins such as the Hercules Citadel and the Roman Colosseum in Wasat al-Balad in Amman. We have been hiking practically every other day, and I am so grateful to be able to keep up with my cohort on these hiking trips. In Wadi Rum, a Bedouin territory in

desert of Jordan, I rode camels, raced through the desert in an open caravan, and slept outdoors in the desert. I did not have any trouble with my asthma or my allergies, in spite of the numerous triggers in this environment! I was able to fully enjoy my time in Jordan—whether I was participating in my refugee advocacy efforts here, or enjoying traveling along Jordan's beautiful and diverse landscape—without worrying about my health, and that is truly thanks to your BREATH program. Thank you so much for your continued help."
-Anisa Rahaman, AAFA-STL BREATH Client

# Making a Difference, One Class at a Time!

"Recently, I went through my second educational institution where one of AAFA-STL's educational classes has been beneficial. I started with my child's daycare and it took almost two years (and two incidents where allergens were given to



my child), for them to consider the class, but once done, it seemed like everything went much smoother at the school. Moving up to the elementary school I was very nervous and worried for my child, but the school has not hesitated to contact AAFA-STL for training. Two food allergy classes were done: one for the cafeteria personnel (AllerTrain™) and one for the rest of staff. I had a meeting with all the teachers a couple hours after the training and all were still amazed. **The Headmaster said "the level of awareness has increased 1000%."** They seemed to understand my concerns, and for the first time, I didn't feel like the "crazy mom" helplessly trying to make someone understand that what's healthy for them is poison for my child. Thank you for making my mission a little easier.

-Ella Mihai, Food Allergy Parent

# **Healthcare News: Epinephrine Auto-Injectors & Your Options**

With the recent news of skyrocketing prices of the chief epinephrine autoinjector on the market, EpiPen®, our agency has been contacted by both media outlets and patients alike, asking for additional resources. **Below is a list of resources and information, compiled by our staff, Rising Leaders committee, and AAFA-STL Board member/local allergist, Dr. Amit Shah.** 

#### Mylan Pharmaceuticals (maker of EpiPen®)

- Co-pay coupons are available which can help save up to \$300 on the devices www.epipen.com/copay-offer.
- A Rx assistance program for those making less than 400% of the federal poverty guidelines is available, and can cover the cost of the devices completely.
- Mylan is set to release a generic version of the EpiPen® which will sell for half the price of the normal brand.
- The EpiPen4Schools® program offers schools free devices through 2017 www.epipen4schools.com.

#### **Additional Resources & Updates**

- Rx Outreach has generic epinephrine auto-injectors for \$250/dual pack **rxoutreach.org.**
- GoodRx has coupons for epinephrine auto-injectors, and devices may be purchased for \$125-\$250 www.goodrx.com.
- To ensure the longest life-span of epinephrine auto-injectors, keep at a cool temperature (NOT refrigerated). If your epinephrine auto-injector has expired, do not throw away until you receive a new device (using an expired device is better than not using one at all during an allergy emergency!)
- Engage in a discussion with your provider about the absolute necessity of carrying the device; for those with life-threatening allergies, it is imperative to have one on hand.
- Ampules of epinephrine with syringes may be prescribed as a last resort, but it is not the preferred method, and proper training to administer the medicine in this manner is crucial.
- There are currently 3-4 epinephrine auto-injector clinical trials taking place, and some alternative devices are also being used in Europe.



Pharmacy Retail Prices (2 pack) EpiPen® - \$725

EpiPen Jr® - \$640

Adrenaclick® autoinjector - \$450

Adrenaclick® autoinjector Jr - \$462

Generic - \$430

Epinephrine ampule - \$140

Thank you to Dr. Amit Shah and our Rising Leaders cohort for contributing to this article!

Dr. Amit Shah Allergy & Immunology, Mercy Clinic (Festus/Arnold, MO) 636.933.2900

# We're Offering Food Allergy Training Courses!



AAFA-STL is excited to offer the array of AllerTrain™ accredited food allergen and gluten-free training courses to foodservice professionals and other interested groups in our service area. Reagan Nelson, Program Director, is a certified Master Trainer of the suite of AllerTrain™ courses. If your establishment or group would like to receive training in the AllerTrain™, AllerTrain Lite™, AllerTrain U™, AllerTrain RA™ or AllerTrain K12™ courses, please contact AAFA-STL: Reagan Nelson, Program Director rnelson@aafastl.org or 314.645.2422 ext. 3

# **Meet the 2016 Rising Leaders Class!**

We are pleased to introduce our inaugural 2016 Rising Leaders class, consisting of a diverse group of young professionals in the region. The seven individuals selected for the program will be working closely with AAFA-STL's development team and board committees to offer a new perspective to AAFA-STL leadership. Additionally, the Rising Leaders cohort will have the opportunity to be mentored by AAFA-STL board members and will learn about non-profit operations and leadership.

"We are very excited to see the ideas that will come out of this inaugural group of Rising Leaders, which will help our team at AAFA-STL find new ways to further fulfill our mission and better serve asthma and allergy clients in the Greater St. Louis area," said Abby Cohen, Co-Founder of Sparo Labs and Rising Leaders Chairperson.



Amit Bery, MD - Resident Physician, Barnes Jewish Hospital

I am a PGY-3 Internal Medicine resident at Barnes-Jewish Hospital with plans to pursue a fellowship in pulmonary and critical care medicine. I am interested in pulmonary disease, especially asthma, and doing work in our community.



Justin King – Clinical Research Program Manager, Washington University School of Medicine After learning of the role that AAFA-STL plays in the community for children and families that are affected by the hardships of asthma and allergies, along with the impact of costs of treatment, I quickly grew a sense of admiration for the mission of the organization. Knowing that such a group exists within our community, that is able to help families in need, means a lot to me personally because I have dealt with asthma all of my life. I have always believed in helping others in need, and what better way to help someone than a group of people who you can relate to.



Victoria Ly – Student and Medical Scribe, Washington University in St. Louis (Public Health) I am currently in the application cycle for medical school and taking courses at UMSL. However, I graduated from SLU in 2015 with a B.S. in Public Health and minors in Sociology and Anthropology. I started to get interested in asthma and allergies while earning my B.S. I quickly realized the seriousness of the conditions, and that sufferers can have a reaction simply living their regular lives in a city that does not realize how prevalent these conditions are. When I learned of AAFA-STL, I thought it'd be a great opportunity to learn more and serve others.

Megan Salkeld – Quality Improvement Coordinator, Queen of Peace Center

I received a B.S. in Health Management and Policy from Saint Louis University and I'm currently employed as the Quality Improvement Coordinator at Queen of Peace Center, a non-profit behavioral healthcare provider for women with addiction, their children and families. I am passionate about the mission of AAFA-STL, hoping to raise awareness of the life-saving interventions, education and support available to the community.



Neem Serra – Software Developer, Asynchrony

I'm an iOS app developer with a background in evolutionary biology, and I'm enthusiastic about making the tech world more diverse. I've struggled with asthma my entire life, and I wish that there was a better way to manage it as an adult. After being exposed to technological efforts to revolutionize asthma and other health issues, I became interested in joining the Rising Leaders program for AAFA-STL so that I could use my skills to help others with similar struggles.

Jamie Simpher – Copywriter, 2e Creative

I am a copywriter at 2eCreative—a St. Louis marketing communications agency that specializes in medical and scientific clients. I graduated from the University of Iowa with a degree in marketing, a degree in English, and a French minor. I've done marketing and copywriting for several medical/pharmaceutical brands, including Wing, which was how I found out about AAFA-STL. I'm looking forward to being a part of the Rising Leaders program and helping to make a positive impact in our community.

Ruby Varghese – Student, St. Louis University (Public Health)

I am a junior at SLU studying psychology with minors in public health and health care ethics. After graduation, I'm interested in working in a public health-related, non-profit setting. I was inspired to apply to the Rising Leaders program after reading about the organization's efforts to make change within the St. Louis community through education, advocacy, and programs such as BREATH and RESCUE. As a Rising Leader, I hope to gain experience pertaining to community outreach & advocacy as well as making a positive impact on St. Louis's asthma & allergy population.

Rising Leaders Mission Statement: To become the next generation of leaders who impact the asthma and allergy community through service, collaboration and innovation.

# **Upcoming Volunteer Opportunities**

**Saturday, November 5** - 12th Annual Trivia Night @ JCC Staenberg Family Complex in Creve Coeur (5:00-10:00pm) **Saturday & Sunday, December 17 & 18** - Holiday Gift Wrap @ the St. Louis Galleria Mall (two-hour shifts from late morning through early evening)

Ongoing administrative/office tasks are also available.

For more information on volunteering with AAFA-STL, please contact Emily Vandas, Program and Volunteer Manager evandas@aafastl.org or 314.645.2422 ext. 4

# **Advocacy Watch**

HR 4662 - School-Based Asthma Management Program Act

Amends the Public Health Service Act to increase the preference given, in awarding certain asthma-related grants, to States that allow trained school personnel to administer asthma-related rescue medications, and for other purposes. The bill would permit certain trained personnel in the school to administer asthma medicine during an emergency. HR 4662 is the federal version of Missouri HB 1188, which AAFA-STL helped enact in the State in 2012 (the first State in the country to pass such a law!)

**Senate Bill 677 (Missouri)** - Establishes requirements for certain public entities to keep a stock of epinephrine auto-injectors (EpiPens) for emergency administration. This bill did not pass during the 2016 legislative session. Stay tuned for updates in 2017!



Founded by two St. Louis-area allergists, Dr. Raymond Slavin and Dr. Philip Korenblat, and Marilyn Horst, a Medical Social Worker at Cardinal Glennon Children's Medical Center, AAFA-STL "opened its doors" in 1981. Seeing the tremendous need in the St. Louis community for an organization that could provide underserved children with life-saving asthma and allergy medications, equipment, education and support, Slavin, Korenblat and Horst created the Project Concern program (now called BREATH), which continues to serve uninsured and underinsured kids to this day. A school nurse asthma equipment program, educational, advocacy and other support programs followed, and are key components of AAFA-STL's mission. aafastl.org



# **AAFA-STL Agency Opportunities**



We are seeking two dedicated, mission-focused individuals to fulfill a year of national service through the AmeriCorps VISTA program. These positions will serve St. Clair & Madison Counties (Illinois), and will help improve awareness and participation in AAFA-STL's school nurse RESCUE program through community engagement and capacity building initiatives. **Applications are currently being accepted for the following:** 

-Community Engagement and Asthma Coalition Coordinator

-Community Engagement Coordinator — School Nurse RESCUE Program

**Year of Service Dates:** November 2016 - October 2017

**Location:** AAFA-STL office in St. Louis, MO and Madison/St. Clair Counties (IL) **To Apply:** Visit **https://my.americorps.gov/mp/login.do** and click "search listings" (in red), then enter "collaboration" into the Program Name field.

**Q's?** Contact Amy Trapp, Director of Development atrapp@aafastl.org or 314.645.2422 ext. 6

AAFA-STL is looking for a few good asthma educators! If you are an AE-C, we have opportunities available to provide high-risk asthma client families with asthma education and telephonic asthma coaching through our contract with Missouri Care and Harmony of Illinois.

To Apply: visit aafastl.org/aec

Q's? Contact Reagan Nelson, Program Director rnelson@aafastl.org or 314.645.2422 ext. 3



Allergy N/ & Asthma NET WORK USAnaphylaxis™ SUMMIT 2016

Food Allergy Management Education

stlouischildrens.org/FAME



Allergy & Asthma Network is hosting a FREE USAnaphylaxis Summit for physicians, nurses, educators, school personnel, emergency unit staff, first responders, patients, caregivers, and other community stakeholders on Friday, September 23 @ the Hyatt Regency St. Louis at The Arch. Register at www.allergyasthmanetwork.com/event/USAnaphylaxisSummit\_StLouis.



United Way of Greater St. Louis helps one in three people in the St. Louis region annually. Through United Way's local partnership with more than 170 non-profit agencies, as well as programs and services such as United Way211, STLVolunteer, and others, more than one million people are served by United Way each year! Lend your support during the UW's campaign this September & October - visit www.stl.unitedway.org.

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The 2nd graders @ Green Pines Elementary sold Friendship Flowers again this spring to raise money and awareness for AAFA-STL! They did so to honor classmates with asthma & allergies.



AAFA-STL Executive Director, Joy Krieger at the annual Redbird Rookies health fair.

#### **A Picture Paints a Thousand Words!**



Chris Geronsin (far L, Beverly Hills Pharmacy), his wife and golf group (including former St. Louis Cardinal, Ted Savage, center), after a day on the links at our 28th annual golf tournament, held on July 29 @ Crescent Farms Golf Club. We thank Beverly Hills Pharmacy for their support, as well as the St. Louis Cardinals for their continued participation and support of our events & agency!



Joy, accompanied by AAFA-STL staff members Wendy Chromoga and Emily Vandas, was invited to learn more about the Westlake Landfill and the Bridgeton Landfill in St. Louis County. During the tour, the group learned about the area and the differences between the landfills. Missouri legislators and representatives from Republic Waste Management Company were also present.

AAFA-STL staff members, Amy Trapp, Reagan Nelson and Emily Vandas attended the 9th annual Signature Healthcare Foundation golf tourney this past spring - we are so grateful for the support we receive from the Foundation!



Emma Stapp & friends raised \$241 through her "Buttons to Breathe" project this past May. She sold buttons at school & community events in honor of her friend, Michael Brewer, Jr, and the funds raised benefited our life-saving programs and services.





1500 S. Big Bend Blvd.

Suite 1 South

St. Louis, MO 63117

aafa@aafastl.org

www.aafastl.org

314.645.2422 (p)

314.645.2022 (f)























