Overview

In 2016, Allergy & Asthma Network hosted three USAnaphylaxis Summits across the United States due to the generous support by Mylan Specialty L.P. The summits were held in September 23 in St. Louis, MO; September 30 in Orlando, FL; and October 7 in Henderson, NV. Participants were invited to attend based on their experience, commitment and passion for increasing anaphylaxis awareness. Of the 147 participants, 13 were Anaphylaxis Community Expert (ACE) volunteers. They came from 20 states and Toronto, Canada and included board-certified allergists and pediatricians; allergy-related patient advocate organizations; school nurses; food allergy bloggers; support group leaders; parents of food-allergic children; psychologists and social workers; asthma educators; nurse practitioners; school teachers; and Mylan Specialty L.P. sales and advocacy staff.

After each speaker presentation, participants at each table discussed scenarios related to the topic. The discussion’s purpose was twofold:

- Develop anaphylaxis awareness best practices to share with everyone after the conference;
- Help participants build stronger connections within their state or region.

The following is a summary of the presentations and collective discussion feedback.
Preventive Drug Lists: Counteracting Unintentional Consequences of High–Deductible Health Plans

Tonya Winders, MBA  
*President & CEO, Allergy & Asthma Network, Vienna, VA*

Ms. Winders provided the first presentation at each summit, titled “Preventive Drug Lists: Counteracting Unintentional Consequences of High-Deductible Health Plans.” She approached the concerns that the public shares with the Network about changes in our healthcare system including high-deductible healthcare plans and the high cost of life saving medications.

The Affordable Healthcare Act has been in place for 6 years – the public is seeing some of the impact for the first time since its inception.

- ACA –6 years in place
- Electronic Medical Records are in widespread use
- Physician Payment Models
- Hospital Penalties
- Cost Burden → 18% GDP is not sustainable

**Changes in Healthcare**

- Shift of Costs from Payers & to Patients
- Shift of Costs from Employers & to Employees
- Ultimately this results in a consumer mindset rather than a patient mindset

**Introduction of High Deductible Health Plans (HDHP)**

- >30M Americans now have HDHP
- >$2500 per year out of pocket for health care
- Some families >$8-10,000 per year
- Pharmacy & Medical Benefits subject to plans

**EpiRage 2016**

- Perfect Storm
  - Timing
  - Pain Point
  - Frustration
  - Inadequate Corporate Response
  - Media & Government & Interventions
Recent FARE Survey
- >30% report that their insurance company has denied coverage for EAI
- Almost 50% report that their insurance limits their ability to get the full number of auto-injectors they need
- >20% who purchase EAI’s spend more than $500 per year out of pocket
- Nearly 25% have left EAI prescription unfilled at the pharmacy
- >40% have split up a two-pack to keep EAI’s in separate locations
- >50% have kept EAI’s past the expiration date due to cost

Focus on Solutions
- Drug Price Transparency
- Preventive Drug Lists
  - Government---USPSTF
  - Commercial

Eliminates/Limits out-of-pocket expense Drug Price Transparency

Epinephrine Access & Affordability Task Force
- 6 organizations
- One-year Plan
- USPSTF
- Top 8 Commercial Plans
- Result=>90% of Americans get medication for little or no OOP

Don’t Lose Sight of...
- In 2015, nearly 80% of commercially insured patients using the My EpiPen Savings Card® received EpiPen® Auto-Injector for $0
- Since the start of the EpiPen4Schools® initiative in 2012, more than 700,000 free EpiPen® Auto-Injectors have been distributed, and more than 65,000 schools, approximately half of all U.S. schools, have participated in the program---More than 1,000 lives saved last year alone!
**Why are we here?**
- >15M Americans impacted by LTA
- Economic & Social Burden continues to grow
- >2 Americans die daily from LTA
- It takes us all!
Anaphylaxis Legislation and Forecast

Charmayne M.C. Anderson, MPA
Director of Advocacy, Allergy & Asthma Network

Ms. Anderson presented “Anaphylaxis Legislation and Forecast” at all three summits. During her presentation, she summarized anaphylaxis-related federal and state legislation as well as regulatory matters and other issues.

Review of Federal Laws

- President Obama signed into law the School Access to Emergency Epinephrine Act of 2013 (Public Law 113-48), on November 13, 2013. This law grants preference to eligible states for asthma-related grants and encourages states to pass sovereign legislation that would permit schools to plan for severe allergic reactions, including stocking and administering undesignated epinephrine auto-injectors in case of an anaphylactic emergency. The law includes language regarding personnel training and limited liability.

- On July 15, 2016, President Obama signed into law a short-term FAA authorization bill, FAA Extension, Safety, and Security Act of 2016 (Public Law 114-190). The Senate bill, H.R. 636, included provisions directing the FAA to: 1) evaluate the medical equipment and supplies required on airline flights, and 2) ensure that the required items meet the emergency medical needs of children. The Senate bill specifically mentioned epinephrine auto-injectors. The House bill, H.R. 4441, did not include this language. The final bill includes some policy changes, but avoids many significant changes the House and Senate had been pursuing, including epinephrine auto-injectors in aircraft emergency medical kits. In 2017, Congress will consider a long-term FAA authorization bill.

- Regulatory Matters
  FDA 2015-N-5017, Banned Devices. Proposal to Ban Powered Surgeon’s Gloves, Powdered Patient Examination Gloves and Absorbable Powder for Lubricating a Surgeon’s Gloves; final rule is pending

- U.S. Preventative Services Task Force and Insurers
  Recognition and classification of epinephrine as a preventative medicine.

Review of State Laws and Legislation

- Carry and Self-Administer Epinephrine Laws
  In all 50 states, competent students may carry and self-administer their own epinephrine at school in the event of an emergency.

- State School Stock Laws
  Schools in 49 states, including the District of Columbia, can now stock undesignated epinephrine auto-injectors for anyone experiencing anaphylaxis. The passage of the 2013 Federal School Stock Epinephrine Law had a significant impact on the states. Prior to the federal law passing, only 23 states had enacted similar laws. Within a year, 46 states had passed legislation, and within 2 years 49 states had done so. Hawaii, the only state without this type of law, had legislation pending prior to the end of its legislative session.
Undesignated school stock epinephrine laws typically include language about:
- Annual student authorization renewal requirements
- Liability release form signed by parent or guardian
- Designating trained school staff who may administer epinephrine
- Standing orders for treatment as well as storing stock epinephrine.

Common Concerns with State School Stock Laws
- Costs
- Liability Protection
- Understanding of Law/Implementation

**Public Entity Stock Epinephrine Legislation**
This legislation permits venues (e.g., recreation camps, youth sports leagues, restaurants, amusement parks, sports arenas and day care facilities) to maintain an epinephrine auto-injector, with the intention of reducing the time it takes to get life-saving epinephrine to a person having a sudden anaphylactic reaction.
- Currently, 30 states have public entity laws, including Alaska, Alabama, Arizona, Arkansas, California, Colorado, Florida, Georgia, Idaho, Indiana, Iowa, Kentucky, Maine, Michigan, Minnesota, Nevada, New Jersey, New Hampshire, New York, North Carolina, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, Tennessee, Utah, Washington, West Virginia and Wisconsin. There were 11 states with pending legislation prior to the end of their respective legislative sessions this year.
- All 30 states with laws require entities to adopt training programs prior to stocking and administering epinephrine. Most state laws allow the state health department to establish their own program or use a nationally recognized organization to establish a training program.
- Each state provides liability from negligence claims. This liability protection is for the entity administering, employees involved in the application of epinephrine, and health care professionals who prescribe and dispense the drug. Some states also provide liability protection for the organizations that train individuals in the administration of epinephrine.
Florida, Missouri, and Nevada Updates
At each summit, Ms. Anderson provided an update of the related laws in the state in which we were located.

Florida

- **School Stock Epinephrine Law**
  - **School Emergencies Act (SB 284)** became law in May 2013 and authorizes public schools to purchase and maintain a supply of epinephrine auto-injectors.
  - School districts must adopt a protocol for the administration of epinephrine auto-injectors for emergency use.
  - Supply of epinephrine auto-injectors may be provided to and used by a student authorized to self-administer or trained school personnel.
  - School district and its employees and agents, including a physician providing a standing protocol for school epinephrine auto-injectors, are not liable for an injury to a student arising from the use of an epinephrine auto-injector.

Concerns with Florida School Stock Laws

- **Implementation**
  - Lacking a statewide protocol to ensure schools have access to the school stock of epinephrine.
  - School districts not permitted to apply for non-student-specific epinephrine auto-injectors.

- **Cost**

- **Stock for private schools and daycare centers**

- **Liability Protection**
  - No clear liability protection for prescribing physicians in the law.

- **Public Entity Law**
  - **Emergency Allergy Treatment Act (HB 1131)** became law in June 2014 and allows various public venues to stock epinephrine auto-injectors.
  - Authorized entities include restaurants, recreation camps, youth sports leagues, theme parks and resorts, and sports arenas.
  - Epinephrine auto-injectors may be administered by trained personnel, or non-trained personnel in an emergency with authorization from a medical provider.
  - Liability protections provided to authorized health care practitioners; pharmacists; trainers; those persons who possess, administer, or store an epinephrine auto-injector; and uncertified persons who administer an epinephrine auto-injector.

Missouri

- **School Stock**
  - In July 2006, HB 1245 became law and authorized school nurses to maintain a supply of epinephrine auto-injectors.
  - The prescription must be written by a licensed physician listing the school district as the patient, include the nurse’s name, and be filled at a licensed pharmacy.
  - A school nurse may use an epinephrine auto-injector on any student believed to be having a life threatening anaphylactic reaction based on the nurse’s training in recognizing an anaphylactic episode.
• **Public Entity Stock**
  o Missouri does not have a public entity stock law. However, in August 2015, the *Comprehensive Emergency Medical Services Systems Act* became law and authorized use of epinephrine auto-injectors for first aid or emergency treatment by “an ambulance service, or emergency medical response agency, a certified first responder, emergency medical technical-basic or emergency medical technician-paramedic who is employed by, or an enrolled member, person, firm, organization or entity designated by, rule of the department of health and senior services in consultation with other appropriate agencies.”  
    
    15 MO. REV. STAT. § 190.246.1  

**Nevada**

• **School Stock Law**
  o SB 453 became law in July 2013 and authorizes public or private schools to obtain a supply of epinephrine auto-injectors.
  o School districts must adopt a protocol for the administration of epinephrine auto-injectors for emergency use.
  o Supply of epinephrine auto-injectors may be provided to and used by a student authorized to self-administer or trained school personnel.
  o School district and its employees and agents, including a physician providing a standing protocol for school epinephrine auto-injectors, are not liable for an injury to a student arising from the use of an epinephrine auto-injector.

• **Public Entity Law**
  o AB 158 became law in June 2014 and allows various public venues to stock epinephrine auto-injectors.
  o Authorized entities include restaurants, recreation camps, youth sports leagues, theme parks and resorts, and sports arenas.
  o Epinephrine auto-injectors may be administered by trained personnel, or non-trained personnel in an emergency with authorization from a medical practitioner.
  o Liability protections provided to authorized health care practitioners; pharmacists; trainers; those persons who possess, administer, or store an epinephrine auto-injector; and uncertified persons who administer an epinephrine auto-injector.

**Other Anaphylaxis-Related Legislation**

• **California SB 1067, Retail Food Code Clean Up.** Amends California’s Retail Food Code to comply with changes made by the Food and Drug Administration (FDA) to update the Food Code in 2013; Requires persons in charge of food providers to have adequate knowledge of food-related allergies and to provide proper education for employees. *Bill signed into law on August 25, 2016.*

• **California SB 1258, the Food Allergy School Policy.** Requires each local educational agency to develop and have in place, beginning with the 2017–18 school year, a comprehensive policy with specified protocols to protect pupils with food allergies. *Bill was held in Senate Committee; no further action expected.*

• **Hawaii SB 911, Relating to Latex.** Prohibits the use of latex gloves by personnel working in food establishments, dental health, healthcare facilities, or by personnel providing ambulance or emergency medical services. *Bill signed into law on July 1, 2016.*
Resources

Federal Food Code
A guideline for safeguarding public health and ensuring food is pure, has no inferior added substances and is honestly presented when offered to the consumer. It represents FDA’s best advice for a uniform system of provisions that address the safety and protection of food offered at retail and in food service.  
http://www.fda.gov/Food/GuidanceRegulation/RetailFoodProtection/FoodCode/ucm374275.htm

Allergy & Asthma Network Advocacy Updates
http://www.allergyasthmanetwork.org/advocacy/current-issues/

Interactive interdisciplinary group discussion related to  
“Anaphylaxis Legislation and Forecast”

Needs
- District level involvement, coming on board and educating the locals
- Absence of onsite school nurse and lead nurse
- Training of hesitant personnel
- Extending programs/prescriptions into restaurants
- Parents have many types of insurance (private, Medicare, Medicaid)
- Multiple sets of epi
- Cut out the middle man: Why are people profiting?
- Access and affordability  
  - 30 day limitation in prescription fill, insurance won’t cover
  - Need generic to be available (insurers pay, pharmacy availability)
- School needs multiple EAI s
  - Other settings: After school, camps, daycares
  - Number of patients exponentially increased

Challenges
- Inability to dispense the EAI
- Legislation language
- Training is money/funding choices
- Pharma expiration  
  - Epi has 12 month expiration
  - Inhaler has 2 year expiration
- $ Transparency
- Knowing Lawmakers  
  - Information sessions with parents
- Florida law: Need to have relationship with a patient to write a prescription
- Liability concerns remain
- Lack of stock epi law knowledge from school administrators
• Not a school nurse in every school
• Most who need EAls can’t use the co-pay cards
• Increase in EAI cost
• High Deductible, ACA doesn’t help
• Education for physicians on different types of allergies
• Splitting dual Rxs
• Medicare/Insurance Stipulation
• How will public entities dispose of EAls
Anaphylaxis Research Update

Ruchi Gupta, MD, MPH

Associate Professor of Pediatrics and Medicine, Northwestern Medicine; Director, Food Allergy Outcomes Research Program, Northwestern Medicine; Attending Physician, Ann and Robert H. Lurie Children’s Hospital of Chicago; and ACE volunteer, Chicago, IL

Dr. Ruchi Gupta presented multiple research studies conducted by her and her staff at Northwestern University. These studies were on the following topics:

- Food Allergy Epidemiology
- Economic Impact of Food Allergies
- Allergic Reaction Registries
- Quality of Life
- Food Allergy Labeling Study
- Food Allergy Sensitization and Presentation in Siblings
- Peer to Peer Education Videos
- School Food Allergy Policy Survey

Food Allergy Epidemiology

- **Prevalence**
  
  8% of U.S. children have a food allergy (Two kids per classroom). Of those with food allergy, 30% were allergic to multiple foods

- **Variation by age**

<table>
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<th>Age Group</th>
<th>Peanut</th>
<th>Shellfish</th>
<th>Tree Nut</th>
<th>Milk</th>
<th>Egg</th>
<th>Wheat</th>
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<td>22.2</td>
<td>7.5</td>
<td>5.4</td>
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<tr>
<td>11 – 13 years</td>
<td>28.1</td>
<td>20.4</td>
<td>15.2</td>
<td>17.7</td>
<td>6.6</td>
<td>8.2</td>
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</tbody>
</table>

- **Association of Race and Income**
  
  - African Americans and Asians have increased odds of having a food allergy, but lower odds of being diagnosed by a physician.
  - Hispanics have lower odds of being diagnosed by a physician
- Household income <$50K have lower odds of having a food allergy and lower odds of being diagnosed by a physician

- **US Food Allergy Anaphylaxis Fatalities** *(data collected from 2001-2006)*
  - Peanut: 55%
  - Tree Nuts: 26%
  - Milk: 13%
  - Shrimp: 6%

- **Geographic Variability**
  - North-to-South decline not observed
  - Odds of food allergy significantly higher at more southern and middle latitudes compared to northern states
  - Population density corresponded with prevalence, from 6.2% in rural areas to 9.8% in urban centers

**Economic Impact of Food Allergies**
- Total Annual Cost per Child: $4,184
- Total Annual Cost in the US: $24.8 BILLION

**Allergic Reaction Registries** *(www.reportmyreaction.com)*

*Registry Goal:* To better track and understand what are causing allergic reactions, including anaphylaxis, where these reactions are occurring, and the care that individuals are receiving.

- Currently piloting and refining three separate allergic reaction registries:
  - **Emergency Department (ED)**
    - Results of ED registry *(209 cases)*
      - Fewer Hispanic children received pre-ED epinephrine compared to other children
      - More white children received pre-ED epinephrine compared to children of color
      - Children with Medicaid also received pre-ED epinephrine less compared to children with private insurance
      - Children younger than 12 years old received pre-ED Benadryl less compared to older children
      - Only 19% of Hispanic children received Benadryl compared to 38% of other children
  - **Schools (piloted in three private K-12th grade Chicago schools)**
    - Data captured included student demographics, type of allergen, location where symptoms occurred, symptoms, medication given, and whether the student went to the ED after exposure.

**Quality of Life**
- Parents need to know that their children are safe in whatever setting that they are in, which is a daunting task. This can create stress, anxiety and influence relationships, decreasing the family’s quality of life. Many domains in a family’s life are impacted by food allergies:
  - Day care and school
Food Allergy Labeling Study

*Purpose:* To gather preliminary information regarding consumer perspective of food allergen labeling practices from multiple countries. To share summary data to help advance the dialogue amongst key stakeholders (i.e. food industry, food scientists, clinicians and researchers, government regulators, and patient groups)

*Subjects included:* Those with food allergies, those with family members with food allergies, and caregivers of those with food allergies.

The survey captured information about the prevalence of specific food allergies, severity of reaction, buying practices in response to different type of labeling such as ‘may contain’.

- **Results:** 6,684 respondents: 5,507 (82.4%) from the U.S and 1,177 (17.9%) from Canada
  - Up to 40% of respondents purchase food with common precautionary allergen labeling (PAL)
  - Severe allergic reaction history made respondents less likely to purchase foods containing PAL
  - Canadians had higher odds of buying “may contain allergen” labeling. The US had lower odds of buying products that utilized the “manufactured in a facility that also processes allergen” or “manufactured on shared equipment with products containing allergen”

Food Allergy Sensitization and Presentation in Siblings

*Objective:* Determine prevalence of sensitization and true food allergy among siblings of food allergic children

*Participants:* Eligible families were those having either one or both parents with at least one biological child (ages 0–21 years) with food allergy.

- **Results:** The prevalence of food allergy among siblings of food-allergic children was 13.6%. Milk allergy was the most common among siblings of food-allergic children (5.9%), followed by egg allergy (4.4%) and peanut allergy (3.7%). The prevalence of sensitization to any food among siblings was 53.0%. Sensitization to wheat (36.5%) was the most common among siblings of food-allergic children.

Peer to Peer Education Videos

*Objectives:* To solicit recommendations from children with food allergy regarding desired content and format for a series of three peer food allergy education videos. To develop and produce the first of three peer food allergy educational videos
Survey Findings: Demographics

Have you had a FA reaction around your classmates?

- Yes: 24%
- No: 76%

Have you ever been bullied because of your FA?

- Yes: 36%
- No: 64%

Survey Findings: Perceptions of Peer Food Allergy Knowledge and Support

Do you think your classmates know how to recognize a food allergy reaction?

- Yes: 20%
- No: 80%

If you have had a FA reaction in front of your classmates (N=33), did they know what to do?

- Yes: 9%
- No: 91%
School Food Allergy Policy Survey

Objective: To determine current food allergy policies, including school-wide, classroom, cafeteria, and extracurricular activity policies. By understanding what food allergy policies are working best, we can make stronger recommendations to schools to improve food safety for all children.

Methods: Administered a short online survey regarding food allergy policies to school nurses/administrators who work in both private and public K-12 school systems. Subjects were asked about current policies that are in their schools, if the policy was needed/effective, and any barriers for the policy being implemented.

- Results (demographics)
  - 286 total respondents
    - 92% of respondents were nurses
    - Majority (85%) work at the school they reported on 5 days a week
    - Mean student population: 5,102 students
    - Peanut (93%) and Tree nut (80%) were the top allergens reported
    - In the past year, 64% of respondents had 0 severe allergic reactions while 21% had 1 allergic reaction

- Results (School-Wide)
  - 52% reported that their schools had allergy awareness programs and events.
    - 94% thought that this practice was helpful.
    - Time was the biggest barrier to having this practice used in schools that did not have awareness programs or events.
  - 81% of respondents reported that stock epinephrine was available
    - Of those who reported “no” the biggest barriers were administration/staff resistance (42%) and money (40%)

- Results (Lunchroom-specific)
  - 65% of reported schools have lunch menus with allergen information
    - 96% believed that it was helpful
    - Of those without this policy, 77% believe that it was needed
    - Barriers: limited staff (43%) and time (37%)
  - 62% reported that there were designated areas for students with food allergy to sit and eat lunch.
    - A vast majority (83%) believed that this was helpful
    - 87% reported that there was training of lunchroom staff about food allergies
    - 96% believed that it was helpful
  - 46% respondents reported that food items in the lunchroom were not labeled with allergen information
    - 61% believe that this policy is needed
    - Barriers: limited staff (42%); time (38%)
  - 83% respondents have clear cleaning procedures in the lunchroom
    - 97% believe that this practice is helpful

- Results (Classroom-specific)
  - 59% reported that there are strict food guidelines in the classroom
    - 95% believe that this is helpful
66% reported that there are strict food guidelines for celebrations (holiday and birthday parties)
  - 93% believe that this is a helpful practice

**Top school recommendations:** Food with a clear ingredient label is allowed (52%); No food is allowed (25%)

- **Results (Staff Training)**
  - 96% reported that there is allergy reaction/anaphylaxis training
    - The training is in-person according to 89% of respondents that have this training
    - 97% believe that it is helpful
    - Of the respondents that do not have this training, 89% believe that it is needed
      - Barriers: lack of staff education (67%) and time (44%)
  - 96% reported that there is epinephrine auto-injector training
    - Almost all (98%) believe that it is helpful
    - Nurses (92%) and administrators (75%) are the most likely to be trained

- **Results (After-School Activities)**
  - Almost half (49%) reported that stock epinephrine is not available during after-school activities
    - Of those half, 48% believe that is needed
    - Identified barriers: limited staff (41%) and money (32%)
  - If students are traveling, 64% of respondents reported that stock epinephrine does not travel with them
    - Only 31% believe that this policy is needed
    - Money is the largest barrier (55%)

- **Results (Transportation)**
  - Over half (58%) of the respondents reported that there is an adult on the bus that is trained on how to use an epinephrine auto-injector and/or how to respond to an allergic reaction

**Resources**
- The Prevalence, Severity, and Distribution of Childhood Food Allergy in the United States
- The Geographic Variability of Childhood Food Allergy
- The Economic Impact of Childhood Food Allergy in the United States
- Quality of Life studies
- Food Allergy Videos and Resources
- Food Allergy Research is Making A Difference, Allergy & Asthma Today magazine, Winter 2015
Implementing Strategies for Emergency Anaphylaxis Care

W. Scott Russell, MD  
*Member, American College of Allergy, Asthma & Immunology (ACAAI) Anaphylaxis Roundtable Expert Panel on Addressing Barriers to Emergency Anaphylaxis Care; Assistant Professor, Department of Pediatrics, College of Medicine, Medical University of South Carolina (MUSC); Medical Director of the Pediatric Emergency Department, MUSC; and Medical Director, MUSC Children’s Hospital Inpatient Service Line, Charleston, SC*

J. Wesley Sublett, MD, MPH  
*Member, American College of Allergy, Asthma & Immunology (ACAAI) Anaphylaxis Roundtable Expert Panel on Addressing Barriers to Emergency Anaphylaxis Care; Board-certified Pediatric Allergist, Family Allergy and Asthma; and ACE volunteer, Louisville, KY*

Dana Wallace, MD  
*Member, American College of Allergy, Asthma & Immunology (ACAAI) Anaphylaxis Roundtable Expert Panel on Addressing Barriers to Emergency Anaphylaxis Care; Past President of ACAAI; Past President of Broward County Medical Association; Board-Certified Allergist, Florida Center for Allergy and Asthma Care, Ft. Lauderdale; Associate Clinical Professor, Nova Southeastern & Florida Atlantic University; and ACE volunteer, Ft. Lauderdale, FL*

Stanley Fineman, MD, MBA  
*Member, American College of Allergy, Asthma & Immunology (ACAAI) Anaphylaxis Roundtable Expert Panel on Addressing Barriers to Emergency Anaphylaxis Care; Past President of ACAAI; Board-Certified Allergist, Atlanta Allergy and Asthma Clinic; Adjunct Associate Professor, Department of Pediatrics, Allergy Division, Emory University School of Medicine; and ACE volunteer, Marietta, GA*

This presentation was developed by four authors, listed above, of an article written in the October 2015 edition of the *Annals of Allergy, Asthma & Immunology* titled, “Addressing barriers to emergency anaphylaxis care: from emergency medical services to emergency department to outpatient follow-up”. The presentation’s purpose was to provide summit participants with strategies for improving the diagnosis, treatment and long-term management of anaphylaxis. **Dr. W. Scott Russell** provided the emergency department (ED) physician’s perspective at all three summit locations and the physicians below provided the allergist’s perspective:

- **Dr. J. Wesley Sublett** in St. Louis, MO,
- **Dr. Dana Wallace** in Orlando, FL; and
- **Dr. Stanley Fineman** in Las Vegas/Henderson, NV.

The speakers formatted this presentation as an interactive discussion rather than a typical lecture. Questions were developed on 10 topics and presenters structured the discussion around the questions.
**Topic 1: Definition of anaphylaxis versus systemic reaction versus being “at risk” for anaphylaxis**

**Key terms lack formal definitions**
- **Food allergy:** adverse reaction to a food allergen caused by immunologic mechanisms.
- **Systemic reaction:** An allergic reaction which is not immediately life threatening, is limited to a single organ system, and has cutaneous/mucosal symptoms, if present, extending beyond the immediate area of allergen contact. (*Speaker’s definition*)
- **Anaphylaxis:** a severe, potentially life-threatening systemic hypersensitivity reaction.
- **Allergic reaction:** A local or generalized immunological reaction following contact with a specific allergen to which one has been previously exposed and sensitized. (*Speaker’s definition*)

**Classification of Human Anaphylaxis**
- Immunologic
- Non-immunologic
- Idiopathic

**Diagnostic Criteria (NIAID)**
- Acute onset of an illness (minutes)

*Note: A Higher Proportion of Subsequent Reactions Are Severe and Require Epinephrine*

**Topic 2: Fear of epinephrine. Physicians and patients delay the administration of epinephrine for the treatment of serious allergic reactions, in part, due to fear.**

**Mild adverse effects of epinephrine: May be good**
- Transient pharmacologic effects after a recommended dose of epinephrine by any route of administration include:
  - Pallor, tremor, anxiety, palpitations, dizziness, and headache. These symptoms indicate that a therapeutic dose has been given.
- Serious adverse effects:
  - Ventricular arrhythmias, hypertensive crisis, and pulmonary edema potentially occur after an overdose of epinephrine by any route of administration. Typically, serious adverse effects are reported after intravenous epinephrine dosing


**Cases in which epinephrine caused a fatal event**
*Pumphrey RS. Clinical and experimental allergy: journal of the British Society for Allergy and Clinical Immunology 2000; 30:1144-50*
Topic 3: When to administer the first dose of epinephrine

Guidelines Position Epinephrine as First-line Emergency Treatment of Anaphylaxis
The speakers stated that epinephrine is the first line treatment for anaphylaxis, and cited multiple sets of medical guidelines which support that statement, including the World Allergy Organization (WAO) Anaphylaxis Guidelines, the Anaphylaxis Practice Parameter, the NIAID-Sponsored Expert Panel on Food Allergy, and the International Consensus On (ICON) food allergy. See below for details:

WAO Anaphylaxis Guidelines
• Epinephrine has a primary role in the management of anaphylaxis
• Prompt intramuscular injection of epinephrine, the first-line medication, should not be delayed by taking the time to draw up and administer adjunctive medications, such as antihistamines and glucocorticoids

Anaphylaxis Practice Parameter
• Epinephrine is the drug of choice for the treatment of anaphylaxis
• The appropriate dose of epinephrine should be given promptly at the onset of apparent anaphylaxis

NIAID-Sponsored Expert Panel on Food Allergy
• Epinephrine is the first line treatment in all cases of anaphylaxis
• When there is suboptimal response to the initial dose of epinephrine dosing remains first-line therapy over adjunctive treatments
• Upon discharge, 2 doses of epinephrine auto-injector should be prescribed

ICON Food Allergy
• Epinephrine is the first-line treatment for anaphylaxis
• Upon discharge, 2 doses of epinephrine auto-injector should be prescribed
• Patients must be educated on when and how to use the epinephrine auto-injector device


Maximum effect of epinephrine is before 10 minutes.
Fatal Anaphylactic reactions are often associated with:
- Delay between time of symptom onset and administration of treatment
- History of asthma
- Adverse therapeutic event
- Fatal reactions can be unpredictable

Reasons Patients Report Why They Did Not Use an Epinephrine Auto-injector
- Not prescribed by a physician
- Not affordable/not filed
- Not accessible when reaction occurred
- Previous reaction improved quickly
- Current reaction seemed mild or improved quickly
- Used another medication to treat episode
- Patient taking another medication that interfered
- Didn’t want to go to the ED
- Patient was unsure when to inject or injected too late
- Rapid progression of reaction


**Topic 4: Use of antihistamines and corticosteroids for a systemic reaction or anaphylaxis**

They are never the first line treatment. They are to be considered optional or adjunctive therapy. Antihistamines do not prevent cardio-respiratory arrest or death.

**Topic 5: Initial diagnosis of a systemic/anaphylactic reaction in the Emergency Department**

**Note:** Textbook definition of anaphylaxis is great for allergists; clinical definition is great for retrospective studies; but gut check definition is the best bet for ED practitioners.

As noted on the [ACAAI website in an overview of this topic](#), complexity of diagnosing anaphylaxis is one of the barriers to emergency treatment of anaphylaxis. “Although the NIAID/FAAN Clinical Criteria are helpful for research, education, and risk assessment by allergists, they are of limited value for emergency physicians at the onset of an anaphylactic event. Such an event may include symptoms associated with multiple differential diagnoses. The criteria also offer no guidance for identifying a patient with mild symptoms who may have impending anaphylaxis or who may be at risk of a future event. This adds to the complexity of decision-making around the use of epinephrine by the emergency medical services (EMS) practitioner or ED physician.”
The NIAID Guidelines/Standards of Care are clear:

- Use intra-muscular (IM) epinephrine as treatment of choice
- Upon discharge, Emergency Department staff should provide patient with:
  - Educational instruction
  - A prescription for an epinephrine auto-injector
  - A referral to a specialist


**Do We Practice What We Preach?**

No. Listed below are three studies that show that more work needs to be done in this area:


- Pediatric Health Information System (PHIS) database 1/1/09-9/20/13
- 10,442 patients with ICD-9 diagnosis code for anaphylaxis
- 35 Children’s Hospitals
- Rate of ED diagnosis rose from 5.7-11.7 patients per 10,000 ED visits
- DID NOT MEASURE EPI USAGE...variations measured in adjunctive treatment.


- 124 patients with clinical anaphylaxis
- 54% epinephrine dosing rate
- Antihistamine dosing rate of 92%
- Corticosteroid dosing rate of 78%


- Prevalence of food allergy among children doubled from 1997-2007
- Pre- and post-guideline epi use in the ED 57% and 41%, respectively
- IM route use pre- and post- in ED 6% and 46%, respectively
- Antihistamine use pre- and post- in ED 92% and 93%
- Steroid use pre- and post- in ED 75% and 73%

**Practical Considerations**

- Diagnosis bias?
- Cost of EAI
- Access to subspecialty care
- Time investment to properly educate
- Tryptase level?
- Concern for litigation?
**Topic 6: Treatment decisions based upon time since onset of a systemic reaction.**

The following case studies were proposed for discussion.

**Case Study 1:** A 2 year old female, with known egg and milk allergy, attends a county fair with her parents where she ingested a dinner roll purchased from a food vendor. Within 30 minutes, her parents note she is very irritable, has developed flushing, and has several episodes of emesis. She also appears to be scratching her face around the mouth. She has a history of allergic rhinitis, asthma, and atopic dermatitis.

**Case Study 2:** An 8 year old male, with known peanut allergy, is on a school field trip. His teachers and school administrators are aware of his peanut allergy. He ingests a cupcake given to the students during the field trip. Within 10 minutes, he reports to his teachers his stomach hurts and needs to use the restroom. On the way to the restroom, the child has several episodes of emesis and appears to have several urticarial lesions on his face. The teacher fearing an allergic reaction calls EMS. When EMS arrives, the child still appears flushed, has mild urticarial lesions on his face. The student reports he is feeling better. Patient has a history of allergic rhinitis, asthma, and atopic dermatitis.

**Case Study 3:** A 14 year old asthmatic with known tree nut allergy is at school with friends setting up a stand to sell candy as a band fund. Her teachers and school administrators are aware of her tree nut allergy and asthma. She ingests a coffee flavored chocolate covered protein bar which was given to her by a friend. Within 30 minutes, she reports her stomach hurts and needs to use the restroom. On the way to the restroom, she has several episodes of emesis (vomiting) and develops chest tightness and shortness of breath. She approaches a teacher who calls EMS fearing she is having problems with her asthma. When EMS arrives, the child still appears flushed and tachypneic (rapid breathing). EMS supplies supplemental oxygen, and the student reports it helps her breathing. Upon arrival to the ER, the student’s symptoms have not changed. Patient has a history of allergic rhinitis, asthma, and atopic dermatitis.

**Anaphylaxis Deaths**
- From 2006 to 2009, the overwhelming majority of hospitalizations or ED presentations for anaphylaxis did not result in death, with an average case fatality rate of 0.3%
- Although anaphylactic reactions are potentially life-threatening, the probability of dying is actually very low. 
  

**Anaphylaxis Progresses Rapidly**
- The median time to respiratory or cardiac arrest was 30 min for foods
- The median time to respiratory or cardiac arrest was 15 min for venom
- The median time to respiratory or cardiac arrest was 5 min for iatrogenic (medication) reactions

*Pumphrey et al Clinical and Exp Allergy. 2000 Aug; 30(8):*
Epi First, Epi Fast
- In a retrospective chart review of fatal and near fatal food reactions, 4 of 6 children had mild symptoms for 1 hour or more before severe respiratory compromise developed and death occurred. 

Topic 7: Biphasic reactions

Practice Parameter Summary: Clinical Impact of Biphasic Response
- Patients may require ≥2 doses because of severity, biphasic reactions, or protracted course
- The need for ≥2 doses occurs in ~15% to 35% of patients who received epinephrine
- A 2nd dose can be administered within the 1st 5 minutes of the previous dose
- There is no way to predict who will require ≥2 doses based on the severity of previous events alone

Evidence that Delay in Epinephrine is a Risk Factor in Biphasic Anaphylaxis
- Of those who had a biphasic reactions, the median time from the onset of symptoms to the initial administration of subcutaneous epinephrine was 190 minutes, versus 48 minutes for those without a biphasic reaction
- When comparing patients with uniphasic and biphasic anaphylaxis, there was a significant higher rate of epinephrine use in the uniphasic group
- A time delay to epinephrine treatment longer than 90 minutes from the onset of the initial reaction was significantly associated with a biphasic reaction

Topic 8: Dosing and cost of epinephrine

What is the best and safest dose of epinephrine?
- Emergency department treatment dose of epinephrine (1:1000):
  - mg/kg up to 0.30 ml for children and up to 0.05 for adults administered IM
- Auto-injectors package labeling in USA
  - 0.15 mg for child 15-30 kg
  - 0.30 mg for child >30 kg
- May be safer to treat children <15 kg with auto-injector than with a syringe and bottle of epinephrine, as errors can be made by caretakers
- Optimal dosing regimen is unknown
American Academy of Pediatrics

Calculations

- For a 10 kg child, the 0.15 mg auto-injector delivers a 1.5-fold overdose
- For a 20 kg child, the 0.15 mg auto-injector delivers a 1.3-fold under-dose, and the 0.3 mg auto-injector delivers a 1.5-fold overdose
- For a 25 kg child, the 0.15 mg auto-injector delivers a 1.7-fold under-dose, and the 0.3 mg auto-injector delivers a 1.2-fold overdose

Recommendations

- For child 10 kg to 25 kg: 0.15 mg
- For child >25 kg: 0.30 mg
- For Child between 15 kg and 25 kg with severe past episodes of anaphylaxis: consider 0.30 mg

Note: Canadian Pediatric Society makes very similar recommendations

Epinephrine for child < 10 kg

EAACI

- If child is > 7.5 kg: 0.15 mg autoinjector

Canadian Pediatric Society

- Children < 10 kg: physicians and families will need to weigh the benefits and risks of administering epinephrine via syringes after being drawn up by a family member from small ampules.
- This method has been shown to be both error and delay prone, and family members must be fully competent before choosing this method of administration

Is it ever better to “overdose” epinephrine in children?

- The ideal dose best on weight and available epinephrine auto-injectors is unavailable for many children
- Consider “overdosing” with the 0.30 mg dose when:
  - Asthma is a concurrent diagnosis
  - Culprit food is peanut, tree nut, milk, egg, fish, or seafood
  - Poor access to emergency medical services
  - Dysfunctional family situation
  - History of previous life-threatening reaction
- In infants, the 0.15 mg dose is preferred to no EAI at all


Epinephrine Auto-injectors—How Many?

- Multiple doses of epinephrine are needed by patients with severe or protracted anaphylaxis symptoms that are not relieved by the initial dose and by those with biphasic or multi-phasic anaphylaxis
- In two prospective studies of anaphylaxis after allergen immunotherapy injections
- Patients received epinephrine injections promptly
• Biphasic reactions occurred in 23 and 10% \(^1\,^2\) of the patients
• Additional epinephrine was not given to any patient
• Retrospective ED study, all causes anaphylaxis: > 1 epinephrine injection in 13% \(^3\)
• Retrospective ED study, children, food-induced: > 1 epinephrine injection in 12% \(^4\)


American Joint Task Force of Practice Parameters
• “Two auto-injectors should be provided because up to 30% of patients who develop anaphylaxis will require more than one dose of epinephrine”
• “…emphasize they should carry two epinephrine auto-injectors with them at all times” [Strong recommendation]

World Allergy Organization Guidelines
“...more than one epinephrine injection is needed in up to 23% of adults receiving an epinephrine injection for anaphylaxis; therefore, consider prescribing more than one epinephrine auto-injector...”

Strong Indications for a second EAI—EAACI Guidelines \(^1\)
• Coexisting unstable or moderate to severe persistent asthma & a food allergy
• Co-existing mast cell diseases and/or elevated baseline tryptase concentration
• Lack of access to medical assistance to manage an episode of anaphylaxis due to geographical or language barriers
• Previous requirement for more than one dose of epinephrine prior to reaching hospital
• Previous near fatal anaphylaxis
• If available auto-injector dose is much too low for body weight

1. Muraro et al, Allergy 2014;69:1026-45

Strong Indications for a Second EAI—Australian (ASCIA) Guidelines

Children
• **Two devices** per prescription are routinely recommended.
• This allows one device to be with the patient (or for parental use at home for younger children) and one device to be available for use at childcare or school.

High school students and adults
• Previous hypotensive (low blood pressure) or near fatal anaphylaxis
• Need for more than one adrenaline dose to treat previous anaphylaxis episodes
• Limited access to medical care (e.g. travel or residence in remote areas, perhaps overseas travel in some circumstances
• Patients with systemic mastocytosis
• Where high body mass indicates that the routine 0.3mg adrenaline dose will provide an insufficient dose for adequate treatment

**Low cost epinephrine solutions**
• Don’t really work
• Drawing up epinephrine from an ampule takes too long and the dose is often inaccurate\(^1\)
• Using an unsealed syringe prefilled with epinephrine by the patient's physician has a shelf-life of only 3–4 months \(^2\)

2. Rawas-Qalaji M, Simons FER, Collins D, Simons KJ. Ann Allergy Asthma Immunol 2009; 102:

**In the Real World: Time it takes to draw an ampule of epinephrine**
• Emergency department nurses (*fastest*)
• General duty nurses
• Physicians
• Parents (*slowest*)

**Topic 9: Patients do not always carry their epinephrine auto-injectors**

### Anaphylaxis in America Survey: Current Epinephrine Practices

<table>
<thead>
<tr>
<th>Current Epinephrine Practices</th>
<th>Reported* (N=344)</th>
<th>Confirmed** (N=261)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carry but have never used</td>
<td>21%</td>
<td>22%</td>
</tr>
<tr>
<td>Carry and have previously used</td>
<td>20%</td>
<td>21%</td>
</tr>
<tr>
<td>Prescribed in the past but never used and do not currently carry</td>
<td>7.8%</td>
<td>7.7%</td>
</tr>
<tr>
<td>None of the above</td>
<td>52%</td>
<td>50%</td>
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</tbody>
</table>

*Reported reactions were categorized as those involving ≥ 1 system.
**Confirmed reactions were categorized as those involving ≥ 2 systems with respiratory and/or cardiovascular symptoms or those leading to loss of consciousness, even if only that single system was involved.


### Anaphylaxis in America Survey: Action Plans

<table>
<thead>
<tr>
<th>Provided with an Anaphylactic Emergency Action Plan (If Prescribed Epinephrine)</th>
<th>Reported* (N=344)</th>
<th>Confirmed** (N=261)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>43%</td>
<td>48%</td>
</tr>
<tr>
<td>No</td>
<td>46%</td>
<td>42%</td>
</tr>
<tr>
<td>Do not know/refused to answer</td>
<td>12%</td>
<td>10%</td>
</tr>
</tbody>
</table>

*Reported reactions were categorized as those involving ≥ 1 system.
**Confirmed reactions were categorized as those involving ≥ 2 systems with respiratory and/or cardiovascular symptoms or those leading to loss of consciousness, even if only that single system was involved.

Atlanta Allergy & Asthma Survey, “Show Us Your Epi”
Survey of Patients in a Private Allergy Clinic (Dr. Stanley Fineman)

- 387 pts previously given Rx for EAI
- Had EAI at visit: 75%
- Had 2 doses of EAI at visit: 49%
- Pts >18 yo with EAI: 79%
- Pts <18 yo with EAI: 70%

How can clinicians improve patient care?

- Review use of epinephrine with each visit
- Ask to see patient’s epinephrine auto-injector
- Review patient’s knowledge of auto-injector use
- Anaphylaxis action plan for all patients at risk
- Encourage family members to come to appointments.

**Topic 10: Treatment of 1st episodes of anaphylaxis in the community setting**

Case Study
A 10 year old male develops cough and wheeze and collapses on the playground while playing flag football during recess. Patient with history of asthma but no history of allergic reaction. No rash, nausea or vomiting. Teacher runs to patient with an AED and an EAI...

Resources

- ACAAI’s Addressing Barriers to Emergency Anaphylaxis Care Expert Roundtable Panel
- ACAAI Anaphylaxis Preparedness Questionnaire
- Illinois Department of Public Health Emergency Epinephrine Act Physician Toolkit
- Why Early Epinephrine is Critical
- Ask the Allergist: Better Safe Than Sorry
- Anaphylaxis Community Expert (ACE) volunteers can partner with Emergency Medicine practitioners
- ACE Spotlight: Don’t Delay Anaphylaxis Treatment—Even in Hospitals
- ACE Spotlight: Epi in the ER
- ACE Spotlight: In an Emergency, ‘Epi First, Epi Fast’
Interactive interdisciplinary group discussion related to
“Implementing Strategies for Emergency Anaphylaxis Care”

Policy and training needed to maximize ED care

- No latex use in hospitals
- ED and EMS staff need to be better educated about identifying and treating anaphylaxis
- EMS
  - All ambulances need EAls
  - Concern: Cost to communities
  - Begin with materials and consistency of supplies
  - Who can administer epi?
- ED
  - Education for diagnosing anaphylaxis
  - Provide epi prescription until further assessment
  - Clear documentation in electronic medical record (EMR) and shared access
  - Connecting circle of treatment (ED communicates to school nurse)
  - Parent and patient education is needed.

Concerns

- EMS drivers who see kids feeling fine and don’t want to take the child to the hospital.
- Cost of EMS to families, can be a deterrent
- Cost of ED to families
- HIPPA
- If I give epi, the person will go to the ER
Implementing a National Food Allergy Management & Education (FAME) Program

This presentation was given by two FAME staff members:
- Lisa Glover-Jones presented in Orlando, FL and Las Vegas/Henderson, NV
- Kathleen McDarby presented in St. Louis, MO

Lisa Glover Jones, MPT
Supervisor, Healthy Kids Express Mobile Health Unit Program, St Louis Children’s Hospital, St. Louis, MO

Kathleen McDarby, RN, MPH
FAME Program Manager/Clinical Nurse Specialist, St. Louis Children’s Hospital, St. Louis, MO

Needs Assessment
Since there was a lack of standardized food allergy knowledge, education and resources for school nurses, St. Louis Children’s Hospital conducted a needs assessment for parents and school nurses. The data showed a need for a comprehensive school-based food allergy program. Staff sought out expert advice from local, regional, and national stakeholders, established an advisory board, and used evidence-based resources and materials to create a manual and pilot program, the Food Allergy Management & Education (FAME) Program and Toolkit.

St. Louis Children’s Hospital’s Food Allergy Management & Education (FAME) Program
- Provides schools with the components of a comprehensive food allergy program to promote best practices
- Offers resources and materials to schools and families across the country on creating a safe, nurturing educational environment for children with food allergies
- Increases awareness that children with asthma and food allergies have an increased risk of anaphylaxis which is a rapid, severe allergic reaction. It can cause difficulty breathing, swelling, dizziness, and even death.

The program’s target audience includes school nurses, administrators, principals, teachers, lunch/recess monitors, paraprofessionals, nutrition services, transportation providers, parents/guardians, and students.

FAME Toolkit
Designed to help school nurses, school administrators, principals, teaching staff, support staff, school nutrition staff, parents/guardians, and students with and without food allergies learn:
- How to create a safer school environment.
- How to recognize and respond to an allergic reaction.
- Steps to avoid food allergens in the school environment.
- Elements to include in a comprehensive school based food
Program Timeline

2008-2009
- Received initial funding and developed the Regional Food Allergy Advisory Board

2009-2010
- MO House Bill 922 passed and Missouri model policy was developed;
- Staff created the food allergy manual and determined the program’s name
- 5 schools were selected to implement the pilot study

2010-2011
- The manual was revised to include pilot study recommendations
- The Regional toolkit was developed
- 180 food allergy manuals and toolkits were distributed at Missouri Association of School Nurses conference.

2011-2012
- The National Advisory Board convened
  o Comprised of school nurses, school administrators, clinicians, legal representatives, parents, organizations

2012-2013
- National FAME Manual & Toolkit released
- Pilot study in schools throughout country
- 508 school districts from around the country participated in the pilot
- School health professionals were the largest group of participants (72%)

How to Use the FAME Toolkit

- **Step 1: Introduction** – All users should begin by reading general food allergy awareness, how to prepare/respond in an emergency, and federal/state laws.
- **Step 2: Next** – Review the section that represents your role in managing students with food allergies. The tool-kit is designed in color coded sections that pertains to the various roles in the school. Each section contains: checklist, forms, and education and training resources.
- **Step 3: Follow Checklist** – The checklist outlines items to review and complete based on role specific responsibilities.
- **Step 4: Use Forms** – A variety of sample forms are included that help obtain detailed information on students with food allergies. For example: student health history and emergency action plan. *Note: all forms may be modified or used in their original format.*
- **Step 5: Review Educational/Training Resources** – Use materials found in the FAME tool-kit to teach yourself and train others about food allergy management. Each section contains summary pages (print as posters to post around school), such as:
  o Cross Contamination/Cross Contact – reviews some common ways cross contamination/ cross contact can occur.
• Food Allergies and Social Factors – reviews the social and emotional effects food allergies can have on students.
• Alternative Ways to Celebrate & Reward Children without Food
• How to Read a Food Label – reviews how to read a food label for the 8 major food allergens.

• **Step 6: Evaluate Educational Training** – Use the food Allergy Questionnaire, a 10 question pre/post questionnaire that can be used to assess knowledge.

**Resources**

- St. Louis Children’s Hospital’s Food Allergy Management & Education Program Toolkit—November 2015
- KFA’s webinar about the FAME toolkit, presented by Kathleen McDarby and Dr. Michael Pistiner
- FAME Manual—Revised August 2014

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**Interactive Interdisciplinary group discussion related to**

*“Implementing A National Food Allergy Management & Education (FAME) Program”*

**School Stock Epinephrine Challenges/Needs**

- Not available in all schools
- Communication
  - Follow up by ED to school nurse
- Liability concerns
  - Administrators/staff fear liability
  - No provider liability protection
- Enough trained staff and more education
  - Keeping staff up-to-date with training
  - Better definition of anaphylaxis for teachers and staff
  - How to know “when” to administer epi
  - Signs and symptoms, food allergy & location of emergency medication
  - Nervous non-medical staff
  - All school personnel should be trained on EAI administration and CPR
  - Role play
  - Raise awareness of students at risk for attacks
  - Help kids to better advocate for their own health.
    - Encourage students by asking them, “Are you carrying your EAI? May I see it?”
- Only allow school nurses to administer, and not all schools have a fulltime school nurse.
- Cost
  - Training and effective materials
  - Some students carry only one EAI (split packs)
  - Lockboxes
  - Stock epinephrine, limited shelf life
    - No guarantee that “free” EAls for schools will continue
    - Availability and safety of other types of EAIs
    - Refilling stock after use, school district incurs cost
    - Lack of awareness regarding EpiPens4Schools program, more PR needed
- Fear of epinephrine

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Sponsored by:
• Does every child need an EAI at school? Could they be shared?
• Universal Anaphylaxis Action Plan is needed
  o With teacher classroom recommendations
• Need kit that has a breakable lock such as the ones AEDs have
• How to make teaching/learning drills “fun”?
• Understanding insurance, legislation, options etc
• Classroom instruction needs to include school food science national guidelines
• Peanut free schools, other free zones, and peanut aware terminology?
  o Does this mean we won’t need epi?
• National “model” anaphylaxis school plan/policy with release form to communicate with MD
• Access to epinephrine on field trips
• Those with known allergen don’t use/bring their epi to school; rely on school stock
  o Belief that the school nurse has “everything”
• Parents need:
  o Education about epi compliance, potential outcomes
  o Financial assistance
• Private/charter schools have different policies
  o No paid RNs = no stock policies
School Food Allergy and Anaphylaxis Management for the Pediatrician: Extending the Medical Home with Critical Collaboration

Sally Schoessler provided this presentation at all three locations and Dr. Michael Pistiner co-presented in St. Louis and Orlando. Dr. Pistiner did not accept any compensation for his participation in the Summit conferences.

Michael Pistiner, MD, MMS
Pediatric allergist for Harvard Vanguard Medical Associates, a voluntary instructor of pediatrics for Boston Children's Hospital. Co-founder and content creator of AllergyHome, Consultant for the Massachusetts Department of Public Health, School Health Services

Sally Schoessler, MSEd, BSN, RN
Director of Education, Allergy & Asthma Network

Definition of Medical Home:
Medical home is the approach to providing comprehensive and high quality primary care. A medical home should be the following:

- **Accessible:** Care is easy for the child and family to obtain, including geographic access and insurance accommodation.
- **Family-centered:** The family is recognized and acknowledged as the primary caregiver and support for the child, ensuring that all medical decisions are made in true partnership with the family.
- **Continuous:** The same primary care clinician cares for the child from infancy through young adulthood, providing assistance and support to transition to adult care.
- **Comprehensive:** Preventive, primary, and specialty care are provided to the child and family.
- **Coordinated:** A care plan is created in partnership with the family and communicated with all health care clinicians and necessary community agencies and organizations.
- **Compassionate:** Genuine concern for the well-being of a child and family are emphasized and addressed.
- **Culturally Effective:** The family and child's culture, language, beliefs, and traditions are recognized, valued, and respected

A medical home is not a building or place; it extends beyond the walls of a clinical practice. A medical home builds partnerships with clinical specialists, families, and community resources. The medical home recognizes the family as a constant in a child's life and emphasizes partnership between health care professionals and families.

Source: https://medicalhomeinfo.aap.org/overview/Pages/Whatisthemedicalhome.aspx

The Medical Home & Collaborative Care Team includes the student, family, school nurse, school health team, and the healthcare team (primary care and allergists). You always start with the student. The primary care pediatrician is the manager and facilitator of patient-centered medical home. They further the goals of the medical home by leading the child’s healthcare team (along with allergists). They educate the family to partner...
with schools, support reasonable accommodations, and support the school nurse and other members of the health care team.


**Pillars of Food Allergy Management—Prevention**

**Oral Exposure**

- Allergens, hidden ingredients, cross-contact – most allergic reactions start in classroom
  - Younger students: passing saliva, supervision during meals and snacks
  - Older students: risk-taking, peer pressure, bullying, kissing
- Labels must be read, should offer meals without allergens, assist students with choices
- No sharing of food, drink or utensils, no unlabeled food – non-food celebrations
- Strategies to avoid cross-contact, food free classrooms only when necessary
- Periodic check-ins with students and staff

**Skin Exposure**

- Isolated contact on intact skin = no severe or systemic response – skin reactions
- Both children & adults touch eyes, nose & mouth regularly
- Soap & water best – commercial hand wipes good – Hand sanitizer is not
- Non-edible items contain some food allergens – finger paint, play dough, shaving cream
- For young children – skin exposure can quickly become mucosal or oral exposure
- HAND WASHING! Have a cleaning protocol, curricular activities should be food free
- Food free classroom may be needed for younger students – “food aware” preferable

**Inhalation**

- Aerosolized proteins – not odors cause allergic reactions, can be fatal
- Science experiments involving burning/heating of allergens create risk
- Use caution when cooking with food, flours, powders & other small particles of food that can go up in the air
- Avoid food in curricular classroom activities
- Field trips – a mine field of issues for students with allergies – food, activities & more
- Some require prior assessment from the school nurse for special accommodations
- **Law: All students go on the field trip or no students go on the field trip**


**Pillars of Food Allergy Management—Emergency Preparedness**

Even with the best prevention strategies, exposure happens. The entire school needs to be prepared for an anaphylactic emergency.

- Each member of the team needs education and support
- This school and every student needs a plan – specific to each student’s unique experience & needs

**Epinephrine: Treatment of Choice for Anaphylaxis**

**Strategies for Students with Known Allergens**

- Identification of Students with life-threatening allergies (medical documentation)
• Emergency Care Plan in place
• Dual pack of epinephrine auto-injectors
• Self-carried or in safe accessible location
• Delegate epinephrine administration per state guidance

**Strategies for in Place for Unknown Food Allergy**
(Note: 25% of epi administration in school is for people with unknown allergies)

• Need a full time school nurse
  o Standing epinephrine orders in accordance with state law
  o Medication administration and care protocols
  o Stock epinephrine
• Staff trained to recognize signs and symptoms and respond appropriately

**Notes on Epinephrine Auto-Injectors (EAI)**
EAIs come in two doses, 0.3 mg (adult) and 0.15mg (youth). Current recommendation is to change from youth to adult dose when the child weighs 25 kilograms or 55 pounds. EAIs come in twin packs (two injectors) in case the patient needs a second dose for a biphasic reaction. School staff members who are authorized to give epinephrine need to be trained every 6 months.

**An Overview of School Care Plans**

• **Individualized Healthcare Plans (IHP)**
  o Standard of nursing practice
  o Foundation for Emergency Care Plan
  o Based on provider’s orders
  o **Written in nursing language to guide nursing care**

• **Emergency Care Plan (ECP)**
  o Outlines emergency care
  o Based on provider’s orders
  o **Written in lay language to guide non-medical staff to respond to an emergency**

• **Section 504 Plans**
  o Legally binding
  o Written by team – 504 Coordinator
  o **Formalizes accommodations needed to make it through the school day**

• **Individualized Education Plans (IEP)**
  o Usually only used for food allergies when other disabilities exist
  o “Other Health Impaired”

**Anaphylaxis Emergency Care Plan**

• Shared a sample of the ACE Anaphylaxis Emergency Care Plan
• Every student with an order for epinephrine should have an Anaphylaxis Emergency Care Plan

**Emergency Care Plan Considerations**

• Collaborative effort
• Understandable to lay person
• Signs and symptoms
• Second dose of epinephrine
• Need to be evaluated in Emergency Department

• Staff need to be trained
  • Understand plan
  • Be willing to administer the plan

**Best Practice Strategies**
- School Physician in every district
- School Nurse in every building
- Universal staff training
- Include anaphylaxis in emergency drills for staff
- Set up sound lines of communication

**Critical Collaboration**
The most effective management of life-threatening food allergies and anaphylaxis occurs when the medical home, the family home, and the educational home work together as a team for the benefit of the child or adolescent, ultimately affording the student the least restrictive environment with the greatest chance for safety and maximal opportunity to **learn and thrive**.

**Resources**
- [Epinephrine Policies and Protocols Workgroup](#)
- [ACE Spotlight: Many Schools Face Challenges Implementing Stock Epinephrine](#)
- [AAP National Center for Medical Home Implementation](#)

**Article**
Farm to Table: Food and Latex Allergies

Chef Ryan Hutmacher  
*Consulting Chef, Weight Watchers and Founder, Centered Chef Works, Denver, CO*

Chef Gary Jones  
*Culinary Dietary Specialist, Walt Disney Parks and Resorts, Orlando, FL*

Chef Keith Norman  
*Food Safety Manager/Assistant Executive Chef, South Point Hotel and Casino, Las Vegas; and ACE volunteer*

This presentation was provided by three chefs:  
- Chef Ryan Hutmacher in St. Louis, MO  
- Chef Gary E. Jones in Orlando, FL  
- Chef Keith Norman in Henderson/Las Vegas, NV

During the presentation, Chefs Hutmacher, Jones and Norman educated participants about:  
- Restaurant food preparation/service policy best practices for patrons with food and latex allergy  
- Food establishment training programs/policies  
- Where the pitfalls/causes of concern are along the way from when the food is produced on the farm to served on the table and  
- Cross contamination issues.

**St. Louis Summit**

Chef Ryan Hutmacher shared insights about sustainable farming, including free range and pasture raised, hormone- and steroid-free, and ethical harvesting practices. His interest in food allergies was developed after two of his staff members were diagnosed with latex and banana allergies. Chef Hutmacher realized that he needed to educate himself and his staff about allergies and food origins. As a result of his research, he reevaluated his Hazard Analysis Critical Control Point (HACCP) program and implemented new best practices for his staff and guests.

**Hazard Analysis Critical Control Point (HACCP) program**

Definition: A management system in which food safety is addressed through the analysis and control of biological, chemical, and physical hazards with food.  
- Production  
- Procurement and handling  
- Manufacturing  
- Distribution  
- Consumption of the finished product

**What is covered in a basic HACCP Program**
• Types of food contaminants:
  o **Physical**: Broken glass, dust, wrappers, band aids
  o **Chemical**: Pest sprays, fertilizers, cleaning agents, etc
  o **Biological**: Bacteria, rodent excrement, insects

**What needed to be added?**

• Allergens and Latex cross-contamination procedures
  o No latex gloves *(Ok: vinyl, nitrile, polyethylene)*
  o Must have epinephrine auto-injector onsite
  o Recipe binder available to guests and staff
    ▪ Ingredient listing of each recipe
    ▪ Asterisks next to common allergens
    ▪ Recipe software programs
  o Procurement standards
    ▪ Requisition sheets include “products to be avoided” at top
    ▪ Acceptable brands and item types listed
    ▪ Executive and Sous Chefs receive, inspect and sign
    ▪ Know your vendors, go local and seasonal
      ❖ Reduces the number of hands touching product during transport
      ❖ Ensures local, sustainable and ethical practices
  o Compartmentalizing potential allergens
    ▪ Fish and shellfish kept separate fridge
    ▪ Peanuts and tree nuts kept in containers
    ▪ Handle only with gloves/1 time use
    ▪ Produce kept in separate cooler
    ▪ Service walk-through if allergic guest present
    ▪ Compartmentalize cooking areas
  o Allergy free equipment
    ▪ Cutting boards, knives specific to meat, seafood, cheese and produce
    ▪ Clean grill before use for allergic persons
    ▪ Separate washing sinks in presence of allergic person
      ❖ New wash water and clean sink if last minute allergy request is made
      ❖ Hands free sink and soap dispenser
      ❖ Peanut and tree nut free area
  o Disclaimers on menus, websites, contracts and registration waivers
  o Safety signs in kitchen
  o Guest rules sand expectations
    ▪ One must declare their allergies
    ▪ Captain and lead chef notified of specific allergy concerns
    ▪ Kitchen staff adheres to specific of kitchen avoiding risks
    ▪ Read the signs posted during catered events and classes
  o Employee cross-contamination and allergen training
Latex Allergy
Chef Hutmacher gave an overview of latex allergies including:

- Hidden dangers found in restaurants, such as latex gloves and utensils, cross-reactive foods, and latex balloons
- Status of latex allergy-related legislation across the US
- A list of restaurants that have allergen-friendly best practices

Orlando Summit
Chef Gary Jones provided participants with an overview of:

- The scope of Walt Disney Parks and Resorts
  - More than 490 food/beverage locations (124 full service, 285 quick service, 86 nightclubs, lounges and pool bars)
  - More than 13,000 food/beverage cast members; serving 60 million meals annually
  - Health and Wellness strategy: To be the Industry Leader for providing delicious food and beverage to all guests including those with allergies and intolerances
  - In FY2009: 330K special dietary requests; In 2015: 750K special dietary requests
- Latex Allergy Primer
  - “Most complex, confusing allergy discovered to date”
  - Shared what latex is, where it is found, and how it is spread
  - Provided a list of cross-reactive foods (high, moderate, low/undetermined)
  - Creating a latex safe environment
- Allergy Friendly Dining Process
  - High touch, custom and individualized approach.
  - Guests should note any dietary restrictions at the time of their booking. Guests can also speak with a chef or manager at the time of arrival.
  - Process Improvements include allergy menus available at over 120 locations at Walt Disney World® and Disneyland® Resorts, Disney’s Animal Kingdom® Theme Park allergy kiosk;
- What’s on the Horizon
  - Allergy friendly menus
  - Disclaimers: “Guest may consult with at chef or special diets trained Cast Member at any time before making a decision”; “We do not have separate kitchens to prepare allergen free items or separate dining areas for Guests with allergies or intolerances”; “Allergen advisory statements (e.g., “may contain”) are not regulated and, for that reason, are not taken into consideration when we are developing allergy friendly meals”; and “Guests with food allergies or intolerances are allowed to bring food items into any Disney theme park or resort.”
  - Allergy-Friendly Buffets, including signage, menu guides and disclaimers
- New Challenges including FODMAPS, FPIES, Birch Syndrome and Lifestyle

Las Vegas Summit
Chef Keith Norman shared his personal philosophy about serving guests with food allergies and educated the participants about best practices at the South Point Resort
Chef Keith Norman’s Personal Philosophy
- As a Chef it is my responsibility to reflect on and challenge my assumptions so I can create more allergen friendly spaces where all allergen guests feel safe. “We must learn to comfortable with being uncomfortable” to create change.
- An allergen patron is not an inconvenience or interruption of service, but rather a humbling opportunity to change a LIFE

Chef Norman’s Service Mission
I create an enjoyable experience for my allergen guest through a genuine attitude that demonstrates my desire to provide excellent quality, efficient service and a safe meal.

Question: What Are We Really Talking About?
Customer Service? Experience after the service? Building Trust?
Answer: An Effective Food Safety Management System that begins at the very beginning of the flow of food.

FDA’S Food Safety Modernization Act (FSMA)
The most sweeping reform of our food safety laws in more than 70 years, was signed into law by President Obama on January 4, 2011.

Purpose: To ensure that the U.S. food supply is safe by shifting the focus from responding to contamination to preventing it. [http://www.fda.gov/Food/GuidanceRegulation/FSMA/default.htm](http://www.fda.gov/Food/GuidanceRegulation/FSMA/default.htm)

FSMA (FARM TO TABLE)
- Accountability
- Allergen Preventive Controls
- Allergen Management Best Practices
- Supply Chain Preventive Control’s QUALIFIED INDIVIDUALS!!!!
  TRAINING TRAINING TRAINING
The Top 8 Allergens

Latex Allergy
Latex allergy is a reaction to certain proteins found in natural rubber latex.
- Latex gloves
- Balloons
- Cross-reactive food

Latex Allergy = Allergy + Anaphylaxis + Food Allergy

Tips for a Safer Dining Experience for Patrons with Life-Threatening Allergies

Before you go:
- Visit the restaurant website and review the menu. Higher risk establishments have buffets (risk of cross-contamination), premade foods (unable for the chef to eliminate an ingredient), and frequently use your allergen.
- Call the restaurant and speak with the manager and briefly share your allergy diagnosis.
- Ask the restaurant the following questions:
  - How does the staff handle special allergy requests?
  - Does staff know the signs and symptoms of an allergic reaction?
  - Does the restaurant carry epinephrine?
  - Has the staff been trained to administer epinephrine?
  - What specific training have the Service and Culinary Teams completed?
  - What standard allergy procedures are in place for Front of House (FOH) and Back of House (BOH)?
  - Complete a “chef card” to give your server.

When you arrive at the restaurant:
- Be aware of your environment. If you are latex allergic, be on the lookout for balloons especially in party or banquet rooms. While Mylar balloons are safe, the presence of latex balloons should prompt a quick exit.

Sponsored by:
• Notify the hostess of your allergy. If you are latex allergic, ask if the kitchen staff uses latex gloves or latex utensils during any aspect of food preparation.
• Notify your server of your allergy and review the menu.
• Give your completed chef card to your server. **With this card, you don’t have to rely only on verbal communication passing from** server to chef.

**Note to Restaurant Staff and Owners, “It may be daunting, but it’s doable”**

**Daunting**
• Food allergy patrons have an everyday *(every minute)* challenge on our hands
• YOU have the same challenge
• It’s fearful for guests to trust you

**Doable**
• Be proactive, not reactive
• Take the lead in your profession
• It’s a *partnership* between you and your FA patrons

**The South Point Keys**
• Create an Allergen Aware Culture
• Empower the Team on all levels, Lead by example
• Education, knowledge and consistent and sustained training
• Trusting the team to actively engage the guest

**Keys to Awareness**
• **Attitude**- Allergen patrons are not an inconvenience
• **Commitment**- Embrace this opportunity not some of the time, not most of the time but all of the time
• **Knowledge**- Is power, understanding an allergen guest’s fear, understanding what an allergen is and what it takes to safely serve an allergen patron.
• **Trust**- Build trust through actions

**South Point Policy-Procedure-Best Practices**
• Massachusetts Allergen Law - model legislation
  - Training Requirement Effective February 1, 2011
• Training and Certification
• Food Allergy Awareness Posters
• Menu Notice

**Restaurant Allergen Standard Operating Procedure**
• Chefs, Managers and Staff must be knowledgeable and aware of not only the top or most common allergens but derivatives and hidden allergens
• This written procedure will allow restaurants maintain consistency throughout the Food and Beverage Departments. Please keep in mind that it only takes a few extra minutes to handle the special request or answer questions from a guest who has a Food Allergy.
• When a patron identifies they have an allergy, the Server should immediately alert the Room Manager, Room Chef.
• A Supervisor speaks directly to the patron.
• Identify the allergy (milk, dairy, eggs, peanuts, tree nuts, fish, shellfish, soy, wheat, latex). As points of reference ask the guest what they normally eat or prepare for themselves at home. This information should be written down verbatim and repeated to the guest to assure accuracy.
• Review the menu items, how to read a label poster posted in your areas, and the complete list of ingredients in the item(s) that you will suggest to the guest. Note: This should be done by the room chef or 2nd cook, as they will be most familiar with the item. Review how these items are actually prepared in the kitchen. This will help avoid chances of cross-contamination.
• Communicate your recommendations to the guest, preferably the Room Chef or 2nd Cook should explain what items are safe to eat. Whenever possible, the Server should be present and your recommendations should be written down.
• When inputting this information, push the alert key which will print in red to the appropriate kitchen station. The Room Chef or 2nd Cook should prepare or directly supervise this preparation. The Manager, Head Host or Host should assist in delivering this meal to the guest in case there are additional questions.

Do not be bashful about the severity of your allergy and the potential consequences if you are exposed. Remember: It's an Allergy not a Preference!

Resources
Food Safety Modernization Act
FDA Food Code

SafeFare
To find a restaurant that has completed a food allergy training program for its employees, visit: www.safefare.org/find-a-restaurant

Disney-Related Emails
• Special.Diets@DisneyWorld.com
• DLRSpecialDiets@email.disney.com
• Special.Diets@DisneyAulaini.com
• DCL.Special.Request.Medical@Disney.com
Interactive interdisciplinary group discussion related to
“Farm to Table: Food and Latex Allergies”

Strategies/Policies that are needed to ensure families are safe when eating out

- Patrons
  - Should always carry their EAI
  - Call ahead
  - Self-advocacy skills with chef, server, manager
  - Personal research
  - Awareness of food ingredients and how food is prepared

- Restaurants
  - Employees need frequent training/education about ingredients, hidden allergens
    - What to do, and why
    - Latex allergy
    - Mock drills
    - Cross-contamination
    - Table cleaning supplies and procedures
  - Stock epinephrine
  - Ingredient lists
  - Good communication between customers and food service staff
  - Encourage safety by assigning a person who is trained to the patron with life-threatening allergies
  - Have a standard allergy policy
  - Use restaurant checklist and guideline book of menu food labels
  - Balloon ban

- Online support
  - App, with updated changes, all ingredients listed
  - Menus and ingredients
  - Use AllergyEats website and apps

- Better labeling
- Advocate for entity stock epinephrine laws in every state
- Anaphylaxis education and cross contamination training needed in restaurants and culinary schools

Note: School lunches and school lunch table cleaning supplies should be in this category
Understanding Risk-Taking Behavior in Adolescents and College Students with Life-Threatening Allergies

Ralph E. “Gene” Cash, PhD, ABPP, NCSP  
Professor of Psychology, Center for Psychological Studies and Director, School-Related Psychology Assessments and Clinical Interventions, Nova Southeastern University, Ft. Lauderdale; and ACE volunteer  
Dr. Cash presented at the Orlando Summit.

Jennifer Moyer Darr, LCSW  
Manager of Outpatient Behavioral Health, National Jewish Health, Denver  
Ms. Moyer Darr presented at the St. Louis and Las Vegas Summits

Dr. Cash and Ms. Moyer Darr shared their experience and expertise in working with teenagers at risk for a life-threatening allergic reaction. They discussed the developmental stage of adolescence and the related issues in working with this age group.

St. Louis and Las Vegas Summits

What do we know?
- Teenagers and young adults make up a high number of the fatal reactions (Bock 2001)
- Asthma, a diagnosed food allergy, and a delay in administering epinephrine are often found to have contributed to fatal food induced anaphylaxis (Bock 2001 and Sampson SA 1992)
- Teens weigh risks and benefits and determine a level of risk acceptability (Mackenzie 2010)

Question: What is adolescence?
Answer: The period in development between the onset of puberty and adulthood. It usually begins between 11 and 13 years of age with the appearance of secondary sex characteristics and spans the teenage years, terminating at 18 to 20 years of age with the completion of the development of the adult form. During this period, the individual undergoes extensive physical, psychological, emotional, and personality changes. (Mosby's Medical Dictionary, 9th edition. © 2009, Elsevier.)

Personality and Coping Style
- Under reporter
- Over reporter
- Anxious avoidance
- Adventurous/risk taker
- People pleaser
- Shy/avoids the spotlight

Food allergic teenagers move between states of denial, experimentation, and overconfidence (Mackenzie 2010)

Developmental Transitions
**Childhood to Adolescence**
- Children are expected to take on more responsibility related to their health care management
- Parent becomes more of a mentor/guide
- Natural consequences, cause and effect
- Separation/Individuation
- Begin to push back and test limits
- Moods/hormones may still be erratic
- Friends (and their opinions) become more important/influential
- Parents may become “stupid” or “embarrassing”

**Young Adult**
- Transition to college/work
- May have left home
- Independent in their medical care
- Planning their future and may question career/family choices based on their health

**Contributors to risk taking and poor adherence**

*“Teens weigh risks and benefits and determine a level of risk acceptability”*

- Increased independence: more time away from parents, more meals outside the home, new experiences, new environments, less adult supervision, lack of medication oversight.
- Cognitive process; Brain is still developing; full comprehension of possible outcomes
- Faulty planning
- Fatigue/Stress
- Developmental and behavioral shifts: invincible, disorganized/ forgetful, “tired of it,” willing to play the odds.
- Social: dating, formals, kissing and sex,
- Cost (special food, Epi)
- Fear (needle, ED)
- Impaired judgment

Alcohol not only inhibit decision making but may also contain the allergen

- Beer and Malt beverages (May Contain Wheat, Nuts)
- Wines (May Contain Sulfites, Eggs, Milk, Fish)
- Gin (May Contain Nuts)
- Vodka (May Contain Wheat, Soy, Nuts)
- Rum (May Contain Dairy, Nuts)
- Cocktails (may contain egg white)
- Amaretto (Almonds)
- Frangelico (Hazelnuts)
- Baileys (Dairy)
- Amarula Cream (Dairy)
Edibles
- Peanut butter cups
- Wheat/Oat/Egg in brownies and cookies
- Dairy in the chocolates

Preparing starts earlier
- Wear a medical alert bracelet/necklace
- Educate peers/friends
- Use scenario based learning with specific symptoms not just “anaphylaxis”
- Help them self-advocate and become empowered
- Checklists, reminder apps/alerts
- Pre-packed bags
- Actual injection experience?
- Understanding accommodations
- Workplace and college accommodations?

References and Resources

Orlando Summit

Food Allergies and Bullying
- According to the World Health Organization, food allergy prevalence worldwide is estimated to be 1-3% in adults and 4-6% in children
- In the US, the prevalence is about 8% among children and adolescents
- Prevalence in the US jumped 18% in the decade from 1997 to 2007
- Food allergy prevalence varies by country, geographical region, race, age, and income
- Bullying of children and adolescents with food allergies also varies by region and country (e.g., 35% of US children, 34% of French children, and 26% of Irish children report being bullied because of food allergies)
- 50% of allergic students in grades 6 through 10 in the US are bullied
- Bullying of food allergic students doesn’t always top after high school (Gupta, et al., 2011; Lieberman et al., 2010; Sentenac et al., 2011; WHO, 2006)
Bullying
Physical, verbal, or written actions that:
- Express hostile intent
- Cause distress to victims
- Are repeated
- Involve a power differential between bullies and victims

The Nature of Bullying
The three main characteristics of bullying are:
- Its intent to cause harm,
- Repetitive nature, and
- The implicit imbalance of power between bully and victim.

The imbalance of power inherent in bullying refers to the victims’ perceptions that they cannot easily defend themselves or stop the interaction.
- As a result, victims are left feeling powerless and vulnerable, which often produces devastating psychological consequences.
- Bullying of children with food allergies isn’t all that different from bullying about other attributes.
- However, children with food allergies must bear an additional burden, because they already have the responsibility of taking care of themselves medically.
  \(\text{Cash, 2010; Olweus, 1993}\)

Results of a U.S. Study
- Among those with food allergies who reported bullying, 86% reported multiple episodes.
- Verbal abuse was the most common form of bullying.
- 82% of these episodes occurred at school, and 80% took place among classmates.
- 21% reported teachers or school staff as the perpetrators.
- 79% said the bullying and harassing were solely related to a food allergy, whereas others reported being harassed for having to carry medication for their food allergy.
- 57% of those bullied reported being touched or harassed by the actual food allergen.

Fortunately, none of the children in the study suffered an allergic reaction as a result of bullying or harassing \(\text{Lieberman et al., 2010}\)

Psychological Effects of Bullying
The impact of bullying in all forms is profound and pervasive, producing -
- Emotional distress
- Underachievement
- Diminished productivity
- Potential physical damage or even death because of injuries, anaphylaxis, or suicide
- Somatization of stress
- 65 % of allergic students who reported being bullied described sadness, depression, or embarrassment \(\text{Lieberman et al., 2010}\)
Medical Risks are Less Common than Emotional Risks
- No reported allergic reactions due to food bullying
- Most reported multiple emotional symptoms
- 67% reported feeling of sadness or depression
- 42% felt that they would continue to be bullied, teased, or harassed due to their food allergies
- Education of students, teachers, and parents on food allergies & recognizing bullying is the first step in reducing bullying in food allergic patients
  
  \textit{(Lieberman et al., 2010)}

Consequences of Bullying
- Studies across multiple countries have found that bullies, victims, and bully-victims fare significantly worse than those who are uninvolved in bullying in terms of health problems and emotional and social adjustment.
- The consequences of bullying experiences can be long-term, sometimes lasting through adolescence into adulthood.
- Bullying can lead to risk-taking behavior in adolescence such as poor self-care, lack of dietary caution, and even suicide attempts
  
  \textit{(Nansel et al., 2004)}

Emotional and Behavioral Problems in Youth with Food Allergies
- Food allergic teens have lower self-esteem and poorer psychosocial outcomes than non-allergic peers.
- Maternal descriptions, but not self-reports, indicate that emotional and behavioral problems are higher among adolescents with food allergies.
- Food allergy is associated with increased odds of depression, anxiety, and Attention-Deficit/Hyperactivity Disorder (ADHD) in adolescence based on maternal reports.
- Depressive symptoms associated with food allergy persist into adulthood.
- Conclusion: Healthcare professionals should seek adolescent and parental perspectives when assessing emotional and behavioral problems.
- Conclusion: Healthcare professionals should monitor the mental health of food allergic adolescents during the transition to adulthood.
  
  \textit{Ferro, Van Lieshout, Ohaton, & Scott (2016)}

Risk Taking Among Youths and Adolescents

Among participants (N=174; 49% male; mean age=16) 75% had peanut allergy, 75% had 2 or more food allergies, and 87% had been prescribed self-injectable epinephrine.
- Regarding risk taking, 61% reported that they “always” carry self-injectable epinephrine, but frequencies varied according to activities: traveling (94%), restaurants (81%), friends' homes (67%), school dance (61%), wearing tight clothes (53%), and sports (43%).
- Fifty-four percent indicated purposefully ingesting a potentially unsafe food.
- Willingness to eat a food labeled “may contain” an allergen was reported by 42%.
- Twenty-nine participants were designated at high risk because they did not always carry epinephrine and ate foods that “may contain” allergens.
The high-risk group, compared with the rest of the participants, felt less “concern” about and “different” because of their allergy and had more recent reactions.

The high-risk group was not distinguishable by age, sex, or number or severity of reactions.

The majority of participants (60%) tell their friends about their allergy, but 68% believe education of their friends would make living with food allergy easier.

*Sampson, Munoz-Furlong, & Sicherer (2006)*

Teenagers and Young Adults With Food Allergy (FA) Use High Risk Behavior to Avoid Bullying

- Food allergic adolescents are at a higher risk of fatal anaphylaxis than other children
- Many food allergic teenagers and young adults intentionally do not carry epinephrine auto-injectors, placing them at great risk
- They say it makes them conspicuous as having a “problem”
- 62% of adolescents and young adults with FAs report teasing due to FA or their auto-injectors
- Auto-injectors do not fit with tight clothing worn for social events
- 92% of teens carry auto-injectors while traveling
- Only 53% carry auto-injectors to social events
- College students do not feel that carrying an auto-injector is important or socially acceptable
- Only 13% of food allergic college students carry their auto-injector
- The longer the time since the last anaphylactic event, the less likely they are to carry their auto-injector
- Peer involvement with FA management may foster facilitative support in social situations

*Marrs & Lack (2013)*

School Accommodations for Allergic Students

- Many, if not most, students with significant allergies are entitled to school accommodations under Section 504 of the Rehabilitation Act of 1973
- Schools are not required to conduct a Section 504 evaluation unless school personnel suspect that a disability exists and that the student is in need of accommodations.
- If, however, the school refuses a parent’s request for consideration of accommodations, the parent has due process rights.
- Accommodations often include extra help in avoiding exposure to allergens, a special “go-to” person for assistance when the student is in distress, the option to get to that “go-to” individual without specific permission in an emergency, protection against deliberate allergen exposure by bullies, authority to carry an epinephrine auto-injector at all times, an anaphylaxis emergency plan, and maintenance of non-student-specific epinephrine auto-injectors at the school.

What Can Parents Do?

- Make sure that your teen’s school has a copy of the allergic reaction treatment plan from your allergist on file.
- Ensure that your child carries an epinephrine auto-injector everywhere he or she goes or that some responsible adult who knows how to use the auto-injector always has one nearby and available for use.
- Determine that your child’s school has effective bullying prevention and anaphylaxis response plans in place.
• If the school does not have these plans, volunteer to help set up either or both.
• Teach your child to read food labels as soon as he/she can read.

Reducing Risk Among College Students
• Keep on top of your healthcare
• Work with Disability Services at your college or university
• Get to know Dining Services
• Live safely in your dorm
• Plan for your social life
• Seek out support

Resources
ACAAI Press Release, July 2014: Make Sure Your Kids And Their Classrooms Are Ready For Back-To-School
FARE Managing Food Allergies at College: A Student’s Guide
Best Allergy Sites: Alcoholic Beverages That Contain Top Allergens
FARE College Pilot Guidelines for Managing Food Allergies in Higher Education
ACAAI Letters to the Editor: School Accommodations for Food Allergic Students
FARE’s College Food Allergy Program
ACAAI Letter to the Editor, Bullying and food allergy: What can allergists do?

Articles

Gupta, RS; Springston, EE; Warrier, MR; Smith, B; Kumar, R; Pongracic, J; and Holl, JL (2011). The prevalence, severity, and distribution of childhood food allergy in the United States. Pediatrics, 128(1), e9-e17.


Sampson, MA; Munoz-Furlong, A; and Sicherer, S.H. (2006). Risk-taking and coping strategies of adolescents and young adults with food allergy. Journal of Allergy and Clinical Immunology, 117(6), 1440-1445.
Interactive interdisciplinary group discussion related to

“Understanding Risk-Taking Behavior in Adolescents and College Students with Life-Threatening Allergies”

Effective strategies to reduce high-risk behavior and enhance self-management for teens

- Keep kids involved in treatment and management from an early age
  - Let teen tell adult how they will be safe/prepared (what is the plan?)
  - Let them decide who their person will be that knows/understand allergen
  - Include allergies when addressing other risky behavior
    - Educate about consequences/benefits
  - Early and continuing education—Small steps, increased responsibility
  - Action plan to include psychosocial component, friends who can assist
  - Engage with other adults/experts
  - Preparing and planning ahead
    - Do it with child
    - Let teen do it with supervision
    - Scenario based learning—Increase comfortableness with practicing administering EAI
  - Use a pre-school checklist and work with school nurse

- Educate peers
  - Enforcement Pal “Hey friend, do you have your pen?”
  - Videos/Tutorials
  - Age appropriate presentations
  - Buddy system/peer support group/online friend group
  - Empowering allergic teens via his friends, getting friends to be proactive and advocate for individual
  - Close friends should know how to use EAI

- Parents should lead by example, demonstrate responsible behavior
- Youth advocacy groups
- Parent/Child Home Assessment/Education Series Study
- School-wide education events
  - Nurse Q/A for EAs to teen students
  - CPR course
  - Integrate topics into school curriculum (peer stress, sexuality education, dating violence)

- Parents should educate themselves to make sure they are giving good advice/information
- Schools should support self-advocacy
- Economically insecure teens need help affording meds, safe food, and managing stress
- Use positive reinforcement
- Doing the right thing at the right time is cool!
- FARE and FAACT teen programs/camps
Conclusion

The USAnaphylaxis Summits serve to bring together national experts in the field of allergy and anaphylaxis with stakeholders, which include allergists, pediatricians, school nurses, patients, patient advocacy organizations and more. Through eight diverse presentations, the latest research and best practice approaches were shared with participants from across the country.

The Summit format is unique in that following each presentation, the participants are given a question that relates to a key issue or an unmet need and are given time for brainstorming and collaboration to generate ideas and strategies to address key concerns in the area of anaphylaxis.

Our national experts provided the foundation for discussion through high level topics, including an update on the latest research, a look at current legislative issues and emergency medical service practice parameters to looking at strategies for educating school staff to allergy management in the restaurant venue. The presentations looked at food allergy, latex allergy and medication protocols across a variety of settings.

The Summit presentations highlighted the meaningful and deep work that has been done in the field of anaphylaxis and addressed the continuing needs for sustainable and continued action for the patients at risk for a life-threatening allergic reaction. Throughout the conference experience, the mission of the Allergy & Asthma Network was advanced – to end the needless death and suffering due to asthma, allergies and related conditions through outreach, education, advocacy and research.