Overview
In 2014, Allergy & Asthma Network hosted four USAnaphylaxis Summits between September 12 and October 17, across the United States due to the generous support by Mylan Specialty L.P. The summits were held in Anaheim, CA; Atlanta, GA; Denver, CO; and Philadelphia, PA. Participants were selected to attend this summit because of their experience, commitment and passion for increasing anaphylaxis awareness. Of the 162 participants, 19 were Anaphylaxis Community Expert (ACE) volunteers. They came from 22 states and one region of 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 nutritionists; a National Association of State Boards of Education representative; and Mylan Specialty L.P. sales and advocacy staff.

In between speaker presentations, participants at each table discussed scenarios related to the previous presentation. 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.
Dr. Gupta presented “Trends in Anaphylaxis” during which she shared anaphylaxis incidence and prevalence data. There is an increasing incidence of anaphylactic reactions—more than 150,000 occur in the United States each year. Although the number of reactions is increasing, the data is sparse and imprecise. In addition there is a lack of a consensus regarding the definition of anaphylaxis.

She shared the following prevalence data:

- 8% of U.S. children have a food allergy (2 kids per classroom).
- Black and Asian races had higher odds of having a food allergy BUT lower odds of being diagnosed by a physician.
- Hispanic race also had lower odds of being diagnosed by a physician.
- People with household incomes of less than $50K had lower odds of having a food allergy and lower odds of being diagnosed by a physician.
- Odds of food allergy are significantly higher at more southern and middle latitudes compared to northern states. Population density corresponded with prevalence. Urban centers had highest prevalence at 9.8% and rural areas had lowest prevalence rate at 6.2%.
- Total annual cost of food allergies in the United States is $24.8 BILLION and total annual cost per child is $4,184.
- Poor quality of life is more likely if the child has been to the Emergency Department for food allergies in the past year, has multiple food allergies, and/or is allergic to milk or wheat.
- Quality of life takeaways include:
  - Food allergy puts a strain on nearly 25% of affected marriages;
  - People who are not impacted by food allergy often do not understand its seriousness;
  - Caregivers of food-allergic children experience concern about social interaction -- their own as well as their children’s;
  - Maternal caregivers report greater empowerment but decreased quality of life as compared to paternal caregiver.
- Management in schools
  - 25% of first-time anaphylactic reactions among children occur at school;
  - Schools must be prepared to accommodate students with food allergies and provide proper treatment in the event of an allergic reaction;
  - Chicago Public Schools data shows that not having a 504 plan can be a barrier to food allergy reporting.

In addition, Dr. Gupta shared a food allergy hospitalization study in Illinois between 2008 and 2012. The key takeaways from this study were:

- Almost 1,700 Emergency Department visits were due to food-induced anaphylaxis, with only 10% hospitalized;
- Average hospital stay was approximately 1.5 days;
Most common allergens to cause hospitalization were peanut, tree nut, fin fish and milk;
Rates of food-induced hospitalizations varied greatly among racial/ethnic groups and by socioeconomic status.

Dr. Gupta also shared risk factors for severe/fatal reactions, which include:
- Reliance on oral antihistamines alone
- Lack or delayed use of epinephrine
- Patient also has asthma
- Lack of skin symptoms
- Denial of symptoms

In addition, Dr. Gupta recommended that health care professionals and schools use Allergy & Asthma Network’s “Anaphylaxis At A Glance” poster when educating parents, patients, and the community about anaphylaxis signs and symptoms.

Discussion Question: What additional research needs exist in the field?
- Genetic links, diversity and cultural
  - How behaviors are linked with genetics
- Impact of school nursing interventions on number of anaphylactic episodes (ER visits) and prevention
- Border studies (Mexico and Canada)
- How do perinatal practices affect food allergies?
  - Perinatal dietary practices of mom
  - Perinatal antibiotic practices
  - Perinatal breastfeeding practice
- What is the cause? Why now? Genetics?
- More research on finding a cure
- Environmental impact, pollution, vicinity of power plants and oil rigs
- Prevalence of food allergies, vegetarians compared to non-vegetarians
- What is the impact of processed food on food allergies
- What is the impact of hygiene obsession on food allergies
- Methods to improve kids compliance for self-carrying epinephrine auto-injectors
- Impact of nationality on food allergies
- Treatment options
- Where do patients feel most comfortable with epinephrine?
- Access and assistance in public places (EMS)
- 504 plan efficacy
- Adult prevalence
- Desensitization
- Comparison of eating habits from 1950s/1960s to now
- Research on fast food ingredients, processes, and distribution
- Cause, change in diet, gut microbes, gut microbes in the United States versus other countries
- Need for more research subjects—alleviate fears around research
- Need for a better working definition of anaphylaxis
- Dispel myths
- Awareness and education
- Overuse of antibiotics
- Is there a way to turn off the allergic switch?
- How much time delay is there when epi is not in arms reach?
- When does food allergy become anaphylaxis for diagnosis and treatment?
- Would epinephrine given in a doctor’s office empower patients/families to use next time if needed?
- Why do people with anaphylaxis survive without epi (“Antihistamine worked”)
- More safety on oral food desensitization, EoE, anaphylaxis, new food allergy diagnosis?
- More data and education related to incidence and severity of reactions specific to each allergen (such as more data and education about egg and wheat and not just nuts)
- Improving management in Emergency Department
- More education about anaphylaxis – it is not just respiratory distress
- Why is food allergy incidence/prevalence rising?
- Treat more than one allergy
- More knowledge to a doctor’s accurate diagnosis and management
- School research on 504 plans
- National guidelines so there’s no need to reinvent wheel
- Antibiotics and food allergies and asthma in infants
- Immunizations in infants and asthma and food allergies
- Types of births (vaginal versus cesarean) and allergies and asthma
- GMOs in food, chemicals, U.S. organic food,
- Component testing: Can you trust the results? And, what are guidelines so testing process is consistent among physicians?
- Increases in auto-immune disease and ADHD and asthma and autism and allergies
- Epigenics
- Twin studies
- What causes anaphylaxis
- Discovering how to eliminate food allergies through the use of a pill
- Testing predicting severity of reactions
- Preventing/managing additional reactions from developing multiple food allergies
- What causes food allergies to develop:
  - Family history
  - Diet
  - Breastfeeding
- Epinephrine temperature stability/keeping epinephrine viable, temperature-wise.
- Where the gut is going wrong
- Research on immune systems and prevalence with allergies
- Is there a correlation with autism and food allergies/EoE?
- Identify barriers to support from non-FA people
- Epinephrine use in oral food challenges
- U.S. foods versus foods in other countries
- Epinephrine administration in school data
- Reaction data
- Communication/literacy
- Management/severity
- Risk-taking behaviors
- Genetically modified foods
- Cultural competency
- Do parents believe food allergies are hereditary?
- Are school nurses comfortable caring for students with allergic reactions?
- Adolescents and barriers to adherence, how to decrease risk taking behaviors
• Empowering children at different developmental levels
• Mentoring programs, building community
• EE/FA’s and correlation with mental/psychological disorders
• Access to Epinephrine Act (mandatory) and study to determine the number of children saved because of the Act.
• Labeling effects

**Significant Unmet Research Needs:**
- Causes of food allergy
- Anaphylactic events in public entities
Ms. Winders presented “The Power of Partnering” at each of the four summits. This presentation was integral as its purpose was to foster collaboration within communities. Participants learned that great partnerships have similarities, including a common mission; complementary strengths; fair division of work and rewards; willingness to risk, accept and forgive; great communication; and willingness to trust and be unselfish.

She shared the strategies for building a great partnership, watching out for pitfalls, and provided an example of a successful anaphylaxis-related partnership.

Access to Emergency Epinephrine in Schools Act

Partners: Mylan Specialty L.P., Pfizer, FARE, AAFA, AAAAI, Allergy & Asthma Network

- Passed the U.S. House on 7/31/2013
- Passed the U.S. Senate on 10/31/2013
- Signed into law on 11/13/2013
  - 44 states have enacted laws which allow or mandate access to stock epinephrine in schools (as of December 8, 2014)

2015 anaphylaxis-related legislation priorities include:

- Focus on 6 remaining states without school-based stock epinephrine laws (HI, IA, NH, NJ, RI, TX)
- Broaden to include entities
- Implement policies once passed
- Reinforce key messages
  - Be aware
  - Be prepared
  - Epi Everywhere! Every Day! Right Away!
- Eliminate anaphylaxis-related mortality rates—save 2 lives per day!

Discussion Question: Who do you create partnerships with?

- Parents—ensure that they are armed with the same information as practitioners and nurses
- Students (needs to carry, identify, communicate)
- Partner with organizations outside health care and allergy organizations (anti-bullying, after school organizations, etc.)
- Local pediatricians and physicians
- National Environmental Health Association and local Health Department
- Primary care physicians, school nurse and administrators, coaches and parents of food-allergic children
- State allergy groups, National Restaurant Association, casinos, American Red Cross
- Local school district
- Local media
- Federal and state legislators, Congressional Caucus
- Community liaisons—No Nuts Moms Group
- Local chapter of American Academy of Pediatrics
- Work with school nurses to provide presentations to pediatricians
- Allergy organizations could provide presentation during physician grand rounds
- School nurses present to Parent Teacher Associations (PTA)
- Use social media to spread word (EpiPens4Schools, free/low cost epinephrine auto-injectors)
With coaches to develop a coaches summit, where coaches, athletic trainers are trained about anaphylaxis
School employees, PTA/PTO
Advocate as an individual when in your own recreation circle (AYSO, Little League, Scouts)

Discussion Question: How do you create effective partnerships within your community?

- Form a state-wide coalition
- Have local school nurse networking groups, schedule regular meetings and share ideas
- Use school and parent newsletters to partner with others
- Increase awareness to carry epinephrine
- Via a nationwide media campaign
- Develop a ‘Mythbusters for Parents’ program; provide information to parents at school; connect the right people to the right information
- Work with a celebrity to promote awareness and preparedness issues
- School nurses communicate with physicians, parents; Emergency Departments communicate with primary care

Significant Unmet Partnership Need:

- National awareness campaign -- mythbusters
Ms. Turner presented “A Current State of Affairs of Stock Epinephrine Legislation” at each of the four summits. She provided the audience with a historical overview of important allergy and asthma laws that served as the foundation for the “School Access to Emergency Epinephrine Act.” Ms. Turner chronicled how the federal law eventually passed both houses of congress and the significance of passage. In addition, in the past 12 months, states have been very effective in getting stock epinephrine laws passed in their own legislatures. Seventeen states passed a form of stock epinephrine legislation last year, bringing the total to 44.

Ms. Turner explained how states gained momentum in an effort to pass their own stock epinephrine laws. She described common concerns that arose in a number of state jurisdictions that if not addressed would have been barriers to passage. Next, she illustrated lessons learned from these efforts and also identified current trends of epinephrine legislation emerging in states.

**Significant Unmet Advocacy Need:**
- Expansion of stock epinephrine to entities
Sally Schoessler, MSEd, BSN, RN, Director of nursing education at National Association of School Nurses Silver Spring, MD. Ms. Schoessler presented at the Anaheim and Philadelphia Summits.

Connie Trent, RN, BSN, Health Services Facilitator at Forsyth County Board of Education; Georgia School Nurses Association 2015 School Administrator of the Year, Cumming, GA. Ms. Trent presented at the Atlanta Summit.

Deborah Pontius MSN, RN, NCSN, Health Services Coordinator and School Nurse for Pershing County School District Member, Board of Directors of Nevada State Association of School Nurses, Lovelock, NV. Ms. Pontius presented at the Denver Summit.

Ms. Schoessler, Ms. Trent, and Ms. Pontius presented “Anaphylaxis Awareness & Preparedness: School Nurse Best Practices” and opened with a statement that students at risk for anaphylaxis need a school nurse. They reiterated the fact that healthy students are better learners—on all levels of academic achievement (performance, education, behavior, cognitive skills, and attitudes).

The presentation was divided into four areas:

- **Values**
  - Assess and make nursing diagnoses
  - Identify measurable and time-bound student outcomes
  - Plan and implement care for students
  - Evaluate children during every interaction

- **Challenges**
  - School nurse to student ratios
  - Number of buildings served by a school nurse
    - 50.4% of school nurses serve one building
    - Nurses reported serving as many as 10 buildings

- **Anaphylaxis — Awareness, Prevention & Treatment**
  - Awareness/Avoidance—School nurses create safe environments, educate staff about anaphylaxis signs and symptoms
  - Prevention—School nurses are essential partners in the development of student emergency care plans and individualized health plans.
  - Treatment—School nurses ensure that staff is ready and willing to follow a student’s emergency care plan. Ideally epinephrine is easily accessible to all who may need to administer it.
    - **Recommendation:** Don’t lock the epinephrine! It should be secure, but unlocked.

- **Moving Forward: Stock epinephrine**
  - Statistics—25% of allergic reactions are first-time reactions—students do not know they have an allergy.
  - Schools need to have stock epinephrine available in schools; staff should be trained and orders should be written. Everyone needs to know what to do in the event of an emergency. Stock epinephrine saves students lives and removes the nursing dilemma.
  - Challenges:
    - Hard to get information out to schools and get policies approved
    - Nurses may be hesitant to teach unlicensed staff to give epinephrine injection
    - Some may choose not to stock epinephrine out of cost concerns or fears
Best practices
- Policy in place for 10 years, and no deaths
- Uses “Get Trained” to train school staff
- Developed state school nurse toolkit

Policies, Protocols, and Reporting
- FAME Toolkit
- NASN Toolkit

Conclusion
School nurses are the experts for maintaining health information, training school staff in proper care, administering an emergency care plan and in administering epinephrine. They play a vital role in allergy management, including management of stock epinephrine and training. Their role is expected to increase. Funding priority should be given for a full-time school nurse position at every school.

Additional resources
NASN’s Position Statement: Role of the School Nurse
NASN’s Webinars, Episode 3: School Nurses: Partnering to Avoid and Respond to Anaphylaxis

Discussion Question: What is your local school nurse to student ratio and how can we advocate more effectively for school nurses?
- Pennsylvania: 1 school nurse:1,500 students
- Chicago: Varies, 1 school nurse per 5 schools
- New York: 1 school nurse :750 students
- Coatsville, PA ratios are higher
- Downingtown Area School District and West Chester PA: There is a school nurse and nurse’s aide at each school but at different levels. Elementary 1 school nurse:500+ students; Middle & High School 1 school nurse:1,000+ students
- Broward County, FL: 50% have rotating nurses
- Ohio: 1 RN per school (500+ students); Private school-volunteer nurse, fulltime.
- Philadelphia school district: Approximately 1 school nurse:800 students. Private PA schools have volunteers and are at 1 school nurse:1,100 students
- New Jersey: 1 school nurse:600 students
- Eastern Tennessee: Largest county has stock epinephrine in all public schools
- FTE Nurse/building, 2-3 nurses rotate buildings and substitute nurses are available
- Some charter schools have 1 nurse 2-3 days per week; and/or only from 8:30-2pm
- Certified School Nurses (New Jersey= Master’s level; Pennsylvania= BSN and certified) 1 school nurse:1,000 students
  - Always a school nurse in the building, but may be a staff nurse
- New Castle, DE public school—1 school nurse per school, sometimes 2 in high schools
  - Private floating nurses, wellness centers/take care clinics nurse practitioners

Significant Unmet School Nurse Need:
- Advocacy and funding for full-time nurses in every school.
Dr. Dana Wallace presented “Causes of Anaphylaxis” at two summits—Atlanta, GA and Philadelphia, PA. By the conclusion of her presentation, attendees learned the common causes of anaphylaxis, discussed some of the new emerging causes, and identified risk factors for the occurrence of and fatality from anaphylaxis.

Dr. Wallace provided background, including incidence and prevalence about the common triggers for food-induced anaphylaxis including peanut, tree nuts, shellfish, fish, sesame, milk, egg, soy, and wheat. She shared some reasons for food allergy fatality rates, including that anaphylaxis may be misdiagnosed as asthma, an unidentified insect reaction, COPD, or heart attack.

Adolescents aged 14-17 are reported to have the highest rate of anaphylaxis mortality. Other risk factors for food allergy fatality are people with an asthma diagnosis (especially if severe), absence of hives, and delayed administration of epinephrine. Eighty percent of food-induced, fatal anaphylaxis cases were not associated with cutaneous signs or symptoms.

Other common causes of anaphylaxis include hidden food allergens in medications, insect stings, and intraoperative, and medications (antibiotics, NSAIDS, acetaminophen, iodinated or MRI contrast media, immunotherapy and vaccines).

New causes of anaphylaxis include chemotherapy drugs, monoclonal antibodies, hereditary angioedema drugs, exercise, allergy injections, sublingual immunotherapy, red meat (affiliated with the bite of a lone star tick), mastocytosis or Mast Cell Activation Syndrome (MCAS)—20-40% of recurrent idiopathic anaphylaxis may have MCAS.

Ruchi Gupta, MD
Dr. Gupta presented “Causes of Anaphylaxis” at the USAnaphylaxis Summits in Anaheim and Denver as a part of her “Trends in Anaphylaxis” presentation. She covered the standard food allergy causes as well as medication, vaccines, latex and venom allergies.
Dr. Gawchik presented “Latex Allergy” at two USAnaphylaxis Summits—Atlanta, GA and Philadelphia, PA. During this presentation, participants learned about the history, prevalence, and types of latex allergy as well as diagnosis, avoidance strategies and treatment protocols. In addition, Dr. Gawchik shared information about latex fruit syndrome and cross-reactive proteins. The foods with the highest rate of cross-reactive proteins to latex are:

- Bananas, Avocados, Chestnut, Kiwi (BACK)
- Apricot, papaya, passion fruit, pineapple, nectarine, plum, cherry, melon, fig, grapes, potato, tomato, celery, and Goji

Latex allergy is diagnosed in patients who have experienced symptoms of allergic reaction (skin rash, hives, eye tearing or irritation, wheezing, itching, difficulty breathing) when exposed to latex or natural rubber products. A patient’s history is crucial to this diagnosis. Things to consider include:

- Workplace association
- Non-workplace association (balloons, dentist, etc)
- Food associated symptoms (bananas, avocado, chestnut, kiwi…)
- Progression of symptoms
  - Contact dermatitis
  - Asthma and rhinitis
  - Anaphylaxis
- History of unexplained atopy or anaphylaxis

Conclusions

- Latex allergy is not uncommon
- It’s a serious health problem
- Establishing a diagnosis can be challenging
- Latex skin test is not available in the United States
- Latex IgE test is not perfect
- Difficult to avoid unless educated
- Premedication does not prevent a reaction
- Cross-reacting foods can be problematic
- Be prepared and educated
Matthew Greenhawt, MD, board-certified allergist at University of Michigan, Food Allergy Program Chair and ACE volunteer, Ann Arbor, MI

Dr. Greenhawt presented “The Risk of Reaction from Public Exposure to Peanut and Tree Nut” at the USAAnaphylaxis Summit in Anaheim, CA. He discussed common myths surrounding life-threatening allergies and presented four clinical studies to demonstrate that the risk of reaction from inhalation or casual contact to peanut or tree nut is exceptionally low. The four studies he highlighted included:

- Casual Contact & Smell - Simonte et al
- Washed Surfaces - Perry et al
- Inhalation - Brough et al
- Environmental Dust - Brough et al

Dr. Greenhawt then presented data about the risk of peanut reactions on airlines as well as data that the following behaviors can reduce a traveler’s personal risk of allergic reaction:

- Make any request
- Request buffer zone
- Request announcement to not eat peanut/nut items
- Request peanut/nut-free meal
- Wipe tray table
- Bring own food
- Avoid use of airline blanket and pillow

The overall theme of the talk reflected maximizing the use of evidence-based practices. One such discussion area was how there is limited focus on prevention and preparedness. He cautioned that we should be wary of advocating and focusing on bans or restrictions, strategies that have no data supporting their effectiveness or nor could they be reliably enforced. This was discussed in the context of data from a recent CS Mott Children’s National Hospital Poll on Health Policy that noted limited support for lunchroom peanut bans among both parents of food-allergic children and parents of non-allergic children. Other examples included using epinephrine and notifying the crew about allergic reactions on airplanes, as opposed to focusing on restricting peanuts being consumed and distributed on-board.

Dr. Greenhawt urged participants to replace fear with fact in crafting and implementing policy decisions, and to involve as many stakeholders as possible when considering such policies.

Drs. Stanley Fineman, Sandra Gawchik, and Michael Pistiner provided similar presentations at the Summits in Atlanta, Denver, and Philadelphia. Their presentation summaries are listed in the subsequent pages.
Dr. Fineman and Dr. Gawchik presented “What are the facts concerning accommodations for food allergies? Is ‘peanut free’ really the answer?” at the USAnaphylaxis Summits in Atlanta and Philadelphia, respectively. Their presentations began with outlining the goals for the session:

- To understand the facts concerning accommodations for food allergies;
- To help you address the uncertainty and fear of food allergy and replace it with facts and empowerment;
- To provide you with practical advice to help maintain the quality of life and safety of the child with food allergy.

Dr. Gawchik shared common peanut allergy misperceptions, including the idea that a peanut-allergic child must be totally isolated from peanut and the psychological impact those misperceptions has on a child as well as on the entire family. Children may fear adverse advents (and death), ridicule and social isolation, have a lower quality of life and more negative impact on school attendance. To coach children with food allergies, we need to help them study the playbook (allergy exposure scenarios) and know where they are vulnerable (understanding their allergy); help them go in with a plan (allergy avoidance); and have a strong defense (allergy action plan/epinephrine). Providing children with basic allergy education can provide an understanding that can help to empower and give a sense of control.

During their presentations, Drs. Fineman and Gawchik presented the medical evidence regarding risk of reaction from public exposure as presented in four clinical studies:

- Casual Contact & Smell - Simonte et al
- Washed Surfaces - Perry et al
- Inhalation - Brough et al
- Environmental Dust - Brough et al

These four studies demonstrate that the risk of reaction is not reduced or eliminated in nut-free environments.

They both shared data about food allergy policies in schools, including a Mott Children’s Hospital poll published in March 2014, which assessed the opinion on possible school-based food allergy policies. The results showed more common ground than previously assumed. Extreme positions were limited on both sides, participants valued limited restrictions, maximum inclusion and their views on labeling and need for guidance was similar.

**School Policy Conclusions**

- Evidence shows risk of public exposure is low
- Evidence non-existent for bans/restrictions
- No state or organization advocates bans (certain policies may have better support in particular age groups)
- Are bans/restrictions simply comfort measures?
- Need to foster awareness of evidence, communication, win-win strategies, and empathy
The presentations were concluded with the need to **A.C.T.**

- Avoid exposure to food allergen
- Communicate needs through the use of an anaphylaxis action plan
  - The child and all caregivers should know about the allergy. All food preparers must know about the allergy. Encourage communication with peers.
  - Practice saying, “No, thank you” and talk about feelings.
- Teach myths and truths about epinephrine as well as know how to use your epinephrine auto-injector. Children should be taught age-appropriate allergy management skills.

Dr. Gawchik also reinforced the need to **R.E.A.ct.**

**R.E.A.ct**

- **R**ecognize anaphylaxis
- **E**pinephrine
  - Educate about epinephrine myths and truths
  - Know how to use epinephrine and how to store it
- **A**ctivate emergency response by calling 911, parents, physician
Michael Pistiner, MD, MMSc, Board-Certified Pediatric Allergist at Harvard Vanguard Medical Associates, Co-Author of Living Confidently With Food Allergy; Co-Founder of AllegyHome.org and ACE volunteer, Boston, MA

Dr. Pistiner presented “Educating and Empowering Our Children About Their Food Allergies” at the Summit in Denver, CO. The goals for his session included to help you address the uncertainty and fear of food allergy and replace it with facts and empowerment and to provide you with practical advice to help maintain the quality of life and safety of the child with food allergy.

Although a difficult balance, allergic reactions can be prevented and dealt with reasonably while maintaining quality of life. To coach children, we need to help them study the plays (allergy exposure scenarios) and know where they are vulnerable (allergy basics); help them go in with a plan (allergy avoidance); and have a strong defense (allergy action plan/epinephrine). Providing children with basic allergy education can provide an understanding that can help to empower and give a sense of control.

Dr. Pistiner explained the two pillars of food allergy management: Prevention and Emergency Preparedness. Prevention involves **A.C.T to prevent** (Avoid, Communicate, Teach)

**Avoid**
- Oral ingestion
  - Avoid exposure to food allergen (known ingredient, hidden ingredient, cross contamination)
  - Read labels. If you can’t read the label, don’t eat it!
- Skin contact
  - Simonte 2003 study showed that isolated skin contact on intact skin did NOT cause severe or systemic reaction.
  - Healthy skin is a great barrier.
- Inhalation
  - Simonte 2003 study showed that inhaling the smell of peanut butter did NOT cause any reaction among 30 peanut allergic children.
  - There are reactions during active cooking that are associated with inhalation of fish, egg, legumes, buckwheat, and milk. Caution is needed with powdered milk, peanut flour, small particles of food.

Dr. Pistiner shared Perry et al, 2004 study which shows that washing hands with soap and water or commercial hand wipes is effective in removing peanut residue. Washing tables with soap and water, commercial cleaners and commercial wipes is effective in removing peanut residue. **What doesn’t work? Hand sanitizers.**

**Communicate**
The child and all caregivers should know about the allergy. All food preparers must know about the allergy. Encourage communication with peers.
- Practice saying “No, thank you” and talk about feelings.

**Teach**
Children should be taught age-appropriate allergy management skills.
Know how to use your epinephrine auto-injector. **Be prepared to R.E.Act.**
**R.E.Act**
- **Recognize** anaphylaxis
- **Epinephrine**
  - Educate about epinephrine myths and truths
  - Know how to use epinephrine and how to store it
- **Activate** emergency response by calling 911, parents, physician

**Additional resources**
- Allergy Home’s [Food Allergy Mortality: The Elephant in the Exam Room](#)
- Allergy Home’s [3 Food Allergy Teaching Points: Let’s Empower Kids](#)

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**Significant Unmet Awareness and Preparedness Needs:**
- Continued reinforcement of key messages
  - Recognize anaphylaxis
  - Epinephrine administration
  - Activate emergency response—Call 911
- Coordinated public policy changes based on fact rather than fear.
Dr. Cash presented “Psychosocial Impact of Life-Threatening Allergies” at the Summits in Atlanta and Philadelphia and began by outlining the various psychological issues which impact people with allergies and their quality of life.

A significant portion of his presentation was allocated to bullying, which is comprised of physical, verbal or written actions that express hostile intent, cause distress to victims, are repeated, and involve a power differential between bullies and victims. Dr. Cash explained:

- Types of bullying
- Prevalence in children worldwide and in the United States
- Consequences of bullying
- Reported acts of bullying patients with food allergies (FA bullying) include:
  - Smear or sprayed with allergic food
  - Safe food mixed with allergic food
  - Spat at with allergic food
  - Kissed with allergic food
  - Water fountain contaminated with allergic food
  - Auto-injectors taken or destroyed

Dr. Cash provided information derived from two studies about food allergy bullying. The two studies were:

- Bullying in Children with Food Allergy—Lieberman et al (2010)
- Food Allergy and Bullying Academic Allergy Patients—Shemesh, E. et al (2013)

In the Lieberman, et al study, 24% of patients reported that they had been bullied, teased, or harassed because of a food allergy. Of these patients, 35% were greater than age 5. Eighty-six percent reported multiple episodes and 79% attributed bullying only due to their food allergy. Results also showed that medical risks were less common than the emotional reported risks.

In the Shemesh et al study, 39% of adolescents (13-17) versus 29% of children (8-12) were bullied due to a food allergy. Children who were bullied for any reason reported this to their parents only 43.5% of the time, while children bullied due to a food allergy who did not report it to a parent, reported to a friend 22% of the time. FA bullying most often took place in school (60%).

Dr. Cash shared the pro and cons of banning allergic food at school as well as the reasons why adolescents and young adults use high risk behavior to avoid FA bullying. He concluded his presentation with various strategies that parents can do to help their children stay safe, how schools can accommodate for children with food allergies, and what physicians can do to support their patients.
Dr. LeBovidge presented “Psychosocial Impact of Anaphylaxis” at the Summit in Denver, CO and explained that the emotional impact and management of food allergies is ongoing and can significantly impact quality of life. She explained the parental burden of managing an overwhelming diagnosis experience, living with risk and uncertainty, balancing safety with social inclusion, and frustration when others “don’t get it”.

Some of the common themes discussed during the presentation include:

- Fear of the unknown is powerful
- What anxiety can look like in food allergic patients
  - Worried thoughts
  - Avoidance behaviors
  - Repetitive behaviors/rituals
  - Misinterpretation of/hypersensitivity to bodily cues
- As children grow older, they may have increased anxiety and uncertainty as they develop a greater cognitive understanding of the risks, are given more responsibility in managing their allergy. Coping strategies must change along with the developmental age of the child.
- Risk taking in adolescence and what influences that risk-taking
- Bullying and teasing
- Discussing safety and risks with children

She concludes her presentation with a series of slides that provide proactive strategies for parents to use when:

- Helping their children build management skills, feel prepared, and solve problems.
- Coping with differences
- Processing what happened after a reaction
- Managing anxiety
Jane Robinson, PhD, Psychologist, Children’s Hospital Colorado, Aurora, CO

Dr. Robinson presented “Childhood Food Allergies: Psychosocial Impact of Anaphylaxis” at the Summit in Anaheim, CA. In her presentation, she shared that the emotional impact and management demands of food allergies are constant and quality of life is lower than in families with other chronic childhood illness (Type 1 diabetes, rheumatologic disease). Anxiety is the key predictive factor for reduced quality of life and that in response to such anxiety, families need to have a balance. Too much vigilance induces fear and anxiety in the child, which impacts trust in the environment, adults and self. Too little vigilance can result in accidental exposure, trauma and/or increased medical intervention.

Dr. Robinson summarized the developmental changes a child experiences as he or she grows from a preschooler to a young adult, and included various vignettes about food allergy-related concerns for each age group. She shared that with greater independence comes greater stress, coping skills, anxiety, problem solving skills, and confidence.

Various scenarios using positive problem solving strategies were discussed as a means for coping with difficult situations. In addition, Dr. Robinson explained the impact of an adolescent’s brain development on their behavior and why there is a great need for them to be prepared by recognizing symptoms and having the ability and confidence to use an epinephrine auto-injector, if necessary.

Her take-home messages included:

- You can find the balance between keeping your child safe and allowing a developmentally appropriate life.
- It is not always easy!
- Never be afraid to ask for help.
- Model positive behavior for your child.
- Let the responsibilities “go” a bit at a time.

**Discussion Question: What are ways to address the psychosocial impact of life-threatening allergies in your child and your community?**

- Sibling/Whole family and community of care taking with balanced transparency
- Role play “adult” situations compassionate and clear communication, doll playing, drawings
- Test “lovingly” situations
- Parent coping skills
- Asking questions to food-allergic kids: What should you do?
- Involving children in planning process for food allergies, i.e. 504 plans (middle and high school students). Child can explain what obstacles they encounter.
- Knowing the plan to deal with food allergies to reduce anxiety
- Helping child identify the positive aspects of food allergy/reaction
- Big/little worries and what to do
- Watch parental anxiety as kids will adopt
- Come up with a plan for movie/sleepover/party (role play)
- Get your child’s friends involved
- Don’t let food allergies define your child/parent. Focus on other things that make them special.
- Looking at it from an age-appropriate perspective
- Open communication
- Help for parents when talking with children

Sponsored by:
- Yoga, for stress relief
- Positive reinforcement
- Make sure food allergy is a component of bullying prevention (Not sure if I interpreted that correctly)
- Children’s books
- Teach the teachers
- Involve respected and widely recognized role models
- Teach all kids
- Initiate awards for bullying prevention activities
- American Girl books
- Support groups for kids at risk
- Bully program:
  - Group gathering at school, sensitivity training, zero tolerance
  - Monthly seminars
  - PNP outreach at school
- Support group presentation:
  - Include psych/social impact
  - Communicate risk and potential mental impact
- How to identify effective anti-bullying program and evaluate its’ success
- Schools/programs appropriate assessment of bullying with food allergies
- Bullies can be victims too
- Food allergy as part of the health curriculum
- Invisible disability, until reaction
- Bullying—developing a standard set of questions asked by allergist/pediatrician “Anaphylaxis Control Test”
- Awareness campaign, emphasize slogans and keywords: Epi Everywhere! Every Day! Right Away!™
- Advise school to have an anti-bullying program for food allergy

**Significant Unmet Psychosocial Needs:**
- School tools to address bullying
- More tools to address parental and child anxiety
- Age-appropriate discussion tool/guide for parents
John Lee, MD, Board-Certified Allergist; Director, Food Allergy Program; Co-Director, Eosinophilic Gastrointestinal Disease (EGID) Program at Boston Children’s Hospital; Co-Founder of AllergyHome.org, Instructor in Pediatrics at Harvard Medical School, and Anaphylaxis Community Expert volunteer, Boston, MA

Dr. Lee presented “Innovative Tools to Educate Your Community: Addressing Challenges to Food Allergy Education” at the USAAnaphylaxis Summits in Atlanta, Denver, and Philadelphia. Tonya Winders, Chief Executive Officer and President of Allergy & Asthma Network, presented this information, using Dr. Lee’s slides, at the Summit in Anaheim.

This session addressed common challenges in the food allergy community and offered resources to address each area of concern.

Discussion Question: What are innovative ways to educate our community/partnerships? Are there additional resources that are needed (what are gaps?)

- Preschool parent/teacher materials
- Student video presentation resources
- Spots to compete with commercials
- School staff training
- Help speaking with boards of education
- How to resolve conflict with other professionals
- More explicit discharge information related to follow up and referral process
- Impact of HIPPA versus need to know
- Multicultural influence on understanding and resources (gap)
- Classroom education, group interactions, growing up/growing through
- Further education among the ENTIRE student body, include in student curriculum
- Education for all parents in school
- Communication and involvement
- Teamwork: Role/outcome in project study groups

Policy Discussion Feedback:

- Barriers: How do you sustain a program, fiscal concerns?
- What is the manufacturer’s cost for auto-injectors? And, why can’t schools/EMS receive this discount?
- School nurses are not in every school
- Florida: clarification of gift giving and stock epinephrine, physician protection/liability
- Federal funding, epinephrine renewal
- Include ACE teams in implementation process
- EpiPen: If the stock is used, will they get a discounted price for replacement/future epinephrine auto-injectors?
- Advisory labels/recall, mislabels
- Color or # code foods by level of allergens
- Training mandates
- Push for mandates (funding concern), collaborate, collect data, address legal concerns, policy creation
- Public entities facilities (college, etc.)
- What do you do to make it mandatory?
  - Help from states like IL and NC
- Cost and auto-injectors shelf life. How to get longer shelf life?

Significant Unmet Education Need:

- National awareness campaign -- mythbusters
Summary of the Significant Unmet Needs:

Allergy & Asthma Network appreciates the continued support of Mylan Specialty L.P. for the USAntaphylaxis Summits. The Summits provide a unique opportunity for multi-disciplinary stakeholders to network, share best practices and brainstorm new ideas to raise awareness and preparedness for life-threatening allergies and anaphylaxis. Listed below are identified needs that are currently unmet in the field. We hope to address these more fully in future summits.

- Causes of food allergy
- Anaphylactic events in public entities
- National awareness campaign -- mythbusters
- Expansion of stock epinephrine to entities
- Advocacy and funding for full time nurses in every school.
- Continued reinforcement of key messages
  - Recognize anaphylaxis
  - Epinephrine administration
  - Activate emergency response—Call 911
- Coordinated public policy changes based on fact rather than fear
- School tools to address bullying
- More tools to address parental and child anxiety
- Age-appropriate discussion tool/guide for parents