



State of Connecticut

Task Force to Study Life-Threatening Food Allergies in Schools

FINAL REPORT

January 4, 2017

TASK FORCE TO STUDY LIFE THREATENING FOOD ALLERGIES IN SCHOOLS

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One appointment remained vacant for the duration of the Task Force:
Certified teacher in a public elementary school

The Task Force to Study Life-Threatening Food Allergies in Schools was established by the CT Legislature in 2015 by virtue of Substitute House Bill No. 6975, Public Act No. 15-17 AN ACT ESTABLISHING A TASK FORCE TO STUDY LIFE-THREATENING FOOD ALLERGIES IN SCHOOLS. The Task Force spent four months (August-December 2016) addressing the charges that were assigned to it.

Those charges were to study life-threatening food allergies in schools by examining:

- (1) the efficacy of the implementation, dissemination and enforcement of the guidelines for the management of students with life-threatening food allergies and glycogen storage disease, developed by the Department of Education pursuant to section 10-212c of the general statutes,
- (2) methods used by school districts to ensure the safety of students with life-threatening food allergies while such students are being transported to and from school,
- (3) the plans for the management of students with life-threatening food allergies and glycogen storage disease, implemented by local and regional boards of education pursuant to section 10-212c of the general statutes, to ensure the safety of students with life-threatening food allergies and their inclusion as fully participating members in the school community,
- (4) the emotional and psychosocial welfare of students with life-threatening food allergies as it relates to and is influenced by such students' membership in the school community and how such students are included or excluded from participating in school events, and
- (5) how instances of isolation or targeting of students with life-threatening food allergies by other students, school staff or school policy are addressed by the school or district administration.

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INTRODUCTION

The Task Force addressed the charge by grouping the five directives into three main areas:

- **Plans, Guidelines and Management in Schools** (directives 1 and 3)
- **Transportation of Students with Life-Threatening Food Allergies** (directive 2)
- **Social-Emotional Well-Being of Students with Life-Threatening Food Allergies** (directives 4 and 5)

To inform itself properly and to address these charges, the Task Force invited the following speakers to make presentations and answer questions in their area of expertise:

Jo Ann Freiberg, PhD
Educational Consultant with the Connecticut State Department of Education

Laurel Francoeur, Esq.
Allergy Law Project Founder

Leslie Sheldon
President, Connecticut School Transportation Association (COSTA)
Operations Manager, All-Star Transportation

Jean Cronin
Vice President, Hughes & Cronin Public Affairs Strategies

Michael Rebmann
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Superintendent, Branford, CT

Kristin Heckt
Superintendent, Bolton, CT

Matt Conway, Ed.D.
Superintendent, Derby, CT

Sharon Locke
Superintendent, Naugatuck, CT

Pat Ciccone
Superintendent, Westbrook, CT

In addition, the members of the Task Force reviewed the following materials:

Connecticut Guidelines for Managing Life-threatening Food Allergies and Glycogen Storage Disease, 2006, 2012 (revised)

Centers for Disease Control and Prevention. Voluntary Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs. Washington, DC: US Department of Health and Human Services; 2013.

Accommodating Special Dietary Needs in School Nutrition Programs, CT State Department of Education, November 2015

CABE Policies to address Accommodating Students with Special Dietary Needs (Five different versions of Policy 5141.25 and one regulation, 2016)

Dear Colleague Letter: Responding to Bullying of Students with Disabilities, from UNITED STATES DEPARTMENT OF EDUCATION OFFICE FOR CIVIL RIGHTS, THE ASSISTANT SECRETARY, dated October 21, 2014

Questions and Answers on the ADA Amendments Act of 2008 for Students with Disabilities Attending Public Elementary and Secondary Schools, from United States Department of Education Office for Civil Rights, dated 1/19/2012

Food Allergy & Anaphylaxis Educational Materials for Connecticut <http://www.allergyhome.org/connecticut/>

National Association of Boards of Education Anaphylaxis Policy Handbook, Customized for Connecticut, November 2014

Connecticut State Department of Education, Health Services Program Information Survey Report, 2015

Public Comment: twenty-five public comments were submitted to the Task Force.

Two separate surveys were conducted by the Task Force for the purpose of evaluating the current practices in school districts in Connecticut:

- Issued by the Connecticut Association of Public School Superintendents
- Issued by Association of School Nurses of Connecticut

Disclaimers:

The Task Force did not have legal counsel during the writing of the report. Each of the three work groups were responsible for drafting reports specific to their assigned directives. These three reports were assembled to form the final report.

Given the focus of the legislation that led to the formation of the Task Force, the members directed attention to life-threatening food allergies and not glycogen storage disease, even though glycogen storage diseases are currently addressed in the Connecticut Guidelines for Managing Life-threatening Food Allergies and Glycogen Storage Disease.

EXECUTIVE SUMMARY

The Task Force was appointed and started work in August of 2016, meeting twelve times. To address the five charges, the Task Force split into three workgroups, each writing a separate report for the final review of the entire Task Force membership.

- **Plans, Guidelines and Management in Schools**
- **Transportation of Students with Food Allergies**
- **Social-Emotional Well-Being of Students with Life-Threatening Food Allergies**

The Task Force voted at the last meeting on all of the recommendations proposed by the workgroups, and only those with a majority vote were included in this report. Thus, while not all of the Task Force members agreed with all of the recommendations, there was majority support for the recommendations that are included and discussed in this report. Of note, there was consensus that the existing Connecticut Guidelines for Managing Life-threatening Food Allergies and Glycogen Storage Disease need to be updated to reflect current medical standards of care, to address the social-emotional well-being of students with life-threatening food allergies and to provide a model plan for districts to use. The guidelines should be aligned with the Centers for Disease Control and Prevention. Voluntary Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs (2013). Additionally, the report *Finding a Path to Safety in Food Allergy: Assessment of the Global Burden, Causes, Prevention, Management, and Public Policy* (National Academies of Sciences, Engineering and Medicine, 2016) was released toward the end of the Task Force's work, and provides additional insights into food allergy management and public policy. Finally, the Task Force unanimously agreed that the guidelines for the management of glycogen storage diseases should be made separate from the guidelines for the management of food allergies in schools, as one condition is characterized by the grave need to avoid certain foods while the other does not.

The Task Force recognized that there are a wide variety of school districts throughout Connecticut, with as many varied communities. As such, it should not be left up to each parent of a food allergic child to advocate for services in isolation and without the oversight of policies and infrastructures to ensure consistency from one district to another. Ideally, policy would balance the unique needs of students who have life-threatening food allergies, the differences in communities throughout Connecticut, and requirements for fair and appropriate education for all students. Organizations such as the National School Boards Association and the Allergy and Asthma Foundation of America have independently concluded that Connecticut's policies are relatively comprehensive.

One of the charges to the Task Force was to evaluate the dissemination, implementation and efficacy of the state guidelines and the implementation of district plans. This proved somewhat difficult in that existing data with the Connecticut State Department of Education (CSDE) did not necessarily address all of these issues. So, the Task Force sought to supplement information through invitations to guest speakers and the dissemination of two surveys – one through the Connecticut Association of Public School Superintendents and the other through the Association of School Nurses of Connecticut. Additionally, written public comment was sought. The Task Force found that although the state of Connecticut is recognized to have comprehensive policies addressing students with life-threatening food allergies, the implementation of these policies needs to be improved.

RECOMMENDATIONS

The Task Force makes the following recommendations based on review of its charges:

For Overall Safety Management and Social-Emotional Well-Being of Students with Life-Threatening Food Allergies:

1. That authorization for students to self-carry an epinephrine auto-injector device be made separate from the authorization to self-administer epinephrine in the legislation.
2. That the use of food for celebrations or rewards be prohibited.
3. That food allergy awareness be integrated into school climate and wellness programs, including providing information for the entire parent/family community on food allergy awareness, management, and acceptance.
4. That standardized annual training for all school staff be required – targeted at specific roles, that must include a review of the district’s allergy plan, allergy awareness, prevention protocols, inclusion, food allergy bullying/harassment/shaming and schools’ emergency response as it relates to anaphylaxis – and include opportunity for in-person review of training topics.
5. That the ability for the parent/guardian to “submit, in writing, to the school nurse and school medical advisor, if any, that epinephrine shall not be administered to such student under this subdivision” PA 14-176 (substitute for 10-212a(a) 2) be eliminated.

For Curriculum:

6. That school culinary programs and course curriculum implement allergen restrictions and safety protocols to allow safe participation for food-allergic students.
7. That the Healthy and Balanced Curriculum framework (circa 2006) be updated to include life-threatening food allergies.
8. That the Family and Consumer Sciences and Culinary Arts Programs/Curriculum be updated to include dietary restrictions, cross-contamination and allergen identification.

For School Food Services:

9. That the serving or selling of peanut, tree nut, or shellfish products or those that may pose possible cross-contamination during processing be prohibited in school before, during, or after school hours; and that mechanisms to prevent direct and accidental exposure to all other known student allergens are ensured.

10. That all food service directors and personnel (outsourced or district managed) be required to complete standardized food allergy training. Training must include overview of food allergies, limitations of Food Allergen Labelling and Consumer Protection Act, how to vet foods for top 8 allergens (potentially 9 if proposed legislation to include sesame as a major allergen passes), avoidance of cross contamination, how to make food substitutions, and effective cleaning and sanitation practices. In addition, food service providers must implement consistent/standardized practices for the accommodation and safety of food allergic students, in compliance with USDA regulations.

For CSDE and DPH:

11. That the Connecticut State Department of Education creates a mechanism to monitor implementation of district food allergy plans based on revised Guidelines.

12. That all districts be required to complete annual survey questions that address implementation of district allergy plans, incidence of anaphylaxis and other food allergic reactions, use of epinephrine, implementation of 504 evaluations, and social-emotional indicators (*modeled after the collection of concussion data in the annual School Health Services survey*).

13. That the Department of Public Health collaborate with the Connecticut State Department of Education to pursue Centers for Disease Control and Prevention funding to promote public awareness and education about food allergies.

14. That the State employs an ombudsperson to serve as an advisory resource and for the reconciliation of disagreements between parents/guardians and districts about 504 plans or district policies that apply to students with life-threatening food allergies.

For Transportation of Students with Life-Threatening Food Allergies:

15. That there shall be training regarding the symptoms and treatment of anaphylaxis, including the administration of epinephrine auto injectors to identified students, provided to all transportation personnel on an annual basis and upon hire throughout the year.

16. That the training shall be the responsibility of the transportation company, possibly utilizing the school nurse or nursing supervisor, EMS personnel, or physicians.

17. That all transportation personnel have specific knowledge of the students on their vehicle who are identified as having food allergies. Identification is to be kept in an obvious location in the vehicle and available to all drivers, including substitutes. This is to be a shared responsibility/collaboration between the student, the parent and/or guardian of the student, designated school personnel, and the transportation company.

18. That all transportation vehicles are equipped with functioning emergency communication devices (e.g. cell phones, two-way radios and/or walkie-talkies). In the event that a vehicle is in a “dead zone” the driver is properly trained to respond to the student experiencing an allergic reaction at any time while being transported.
19. That food is not to be eaten on the school bus or any transportation vehicles unless indicated by an IEP or 504 plan.
20. That, to ensure the safety of students with life-threatening food allergies during school transportation, transportation personnel be mandated to follow the American Academy of Pediatrics Standard of Care.

For Revision of Current CDSE Guidelines:

21. That the Connecticut State Department of Education Guidelines for the Management of Life-Threatening Food Allergies and Glycogen Storage Diseases be updated to reflect current evidence-based practice and promote safety and inclusion of students with life-threatening food allergies. The updated guidelines will include the following essential elements:
 - a. Clarified legal requirements with regard to Section 504, FAPE, USDA regulations for accommodation of food allergic students in school nutrition programs
 - b. A model district plan to facilitate implementation and promote practice according to revised guidelines
 - c. A standardized emergency allergy plan that integrates a medication authorization indicating epinephrine as first-line medical treatment for anaphylaxis
 - d. Specific criteria for foods used as part of a curriculum, including procedures for allergen avoidance and means for including all students
 - e. Specific plans to address the social and emotional aspects of life-threatening food allergies and means for school districts to promote the psychosocial well-being of students with life-threatening food allergies.
 - f. School staff (including but not limited to teachers, paraprofessionals, administrators, related service providers, nurses, cafeteria staff, bus drivers) and students should be provided with education and training regarding risks, reactions, signs, and symptoms, as well as proactive safety and inclusion strategies and practices for students with life-threatening food allergies.
 - g. The roles and responsibilities of school districts and other school personnel as listed in the CDC Guidelines
 - h. If parents choose to opt their child out of an allergen-free table in the cafeteria, the school team and parents will work together to provide the child with a safe alternative that all agree upon
 - i. The recommendation that all students with a known life-threatening food allergy have a 504 plan that includes an Emergency Health Care Plan;

evaluate all other students with reported life-threatening food allergy for medical diagnosis and Section 504 with Emergency Health Care Plan; and promote collaborative partnerships with parents and their healthcare providers to identify accommodations that promote the safety and inclusion of each individual student for all school related activities (including but not limited to regular school day hours, school nutrition programs, transportation, field trips, school-sponsored before and after school activities/events, and athletics

- j. Recommendations for how to make every learning environment safe for all students with known or unknown life-threatening food allergy
- k. Procedures for how to promote no food sharing to minimize the risk of accidental exposure

- 22. That glycogen storage disease guidelines be separated from guidelines for the management of life threatening food allergies (Connecticut State Department of Education Guidelines for the Management of Life Threatening Food Allergies and Glycogen Storage Diseases).
- 23. That, pending guidelines revisions, CSDE issue a circular letter clarifying the need for all districts to comply with existing state and federal legislation, including the requirement for an IHCP and EHCP, and application of Section 504 to all students with known or reported life-threatening food allergy to have accommodations that address the safety and inclusion of each individual student.
- 24. That the work group for the Guideline revisions be co-chaired by a representative from the Connecticut State Department of Education and a member of the Task Force to Study Life- Threatening Food Allergies in Schools and include at least two additional Task Force members, at least one of whom is a parent advocate.

EXTENDED REPORT OF THE TASK FORCE

Background

“Food allergy is a complicated, multi-factorial disease whose causes, mechanisms, and effects are not yet fully understood. The evidence on the true prevalence of food allergy is obscured by insufficient or inconsistent data and variable methodology. Despite these obstacles, public concern has grown in response to the apparent rising global prevalence of food allergies, and many health care experts who provide care to patients agree that any real increase in food allergies that has occurred is unlikely to be due simply to an increase in awareness. Numerous stakeholders are concerned about this rise in food allergies, including the general public, policy makers, regulatory agencies, the food industry, scientists, clinicians, and especially families of children and young people suffering from food-related allergies.”

- *Finding a Path to Safety in Food Allergy: Assessment of the Global Burden, Causes, Prevention, Management, and Public Policy, National Academies of Sciences, 2016*

Symptoms of a food allergy can range from mild to severe, depending on the individual. There is some disagreement about what constitutes a “life-threatening” food allergy. Just because an initial reaction causes mild symptoms does not mean that subsequent reactions will be similar, and more severe symptoms are possible at a later time. Likewise, symptoms may wane over time to each exposure. It is impossible to predict how severe each reaction might be; therefore all patients with food allergies should be carefully counseled about the risk of anaphylaxis, a potentially fatal reaction that is treated with epinephrine (adrenaline).

The most severe allergic reaction is anaphylaxis — a life-threatening whole-body allergic reaction that can impair breathing, cause a dramatic drop in blood pressure and affect heart rate. Anaphylaxis can come on within minutes of exposure to the trigger food, or the onset can be delayed over a period of time. Anaphylaxis can be fatal and must be treated promptly with an injection of epinephrine (adrenaline). As defined by the Americans with Disabilities Amendments Act of 2008, life-threatening food allergies are a federally recognized disability as several major life functions are affected (for example but not limited to eating and breathing).

While any food can cause an adverse reaction, eight types of food account for about 90 percent of all allergic reactions:

- Eggs
- Milk
- Peanuts
- Tree nuts
- Fish
- Shellfish
- Wheat
- Soy

In 2015, 82% percent of Connecticut school districts completed the CSDE Health Services Program Information Survey. The following foods were identified as the top allergens:

- 93.2% of school districts reported one or more children with milk allergy
- 92.6% of school districts reported one or more children with tree nut allergy
- 92.6% of school districts reported one or more children with peanut allergy
- 87.6% of school districts reported one or more children with wheat allergy
- 85.3% of school districts reported one or more children with shellfish allergy
- 83.6% of school districts reported one or more children with egg allergy

In Connecticut, 7% of epinephrine administrations in schools in 2015 were for previously unidentified food allergies (CSDE, Health Services Program Information Survey Report, 2015), indicating that school personnel should be prepared to identify allergic response even in previously unidentified students.

Interestingly, some studies have found teenagers and young adults with food allergies are at the highest risk of fatal food-induced anaphylaxis, presumably because of risk-taking behaviors. This is contrary, and perhaps due to, the common perception that younger children with life-threatening food allergies must be managed more carefully (Sampson HA, Mendelson L, Rosen J. 1992).

In Connecticut schools, 3.6% of students are reported to have life threatening food allergies (CSDE, Health Services Program Information Survey Report, 2015). Nationally, food allergy prevalence is estimated to be between 2.5% and 8% (Gupta, Springston, et. al., 2011).

Food allergy prevalence in the U.S. for specific allergens is estimated to be (Food Allergy Research and Education, Inc., "Facts and Statistics"):

Peanut: 0.6-1.3%

Tree nuts: 0.4-0.6%

Fish: 0.4%

Crustacean shellfish (crab, crayfish, lobster, shrimp): 1.2%

All seafood: 0.6% in children and 2.8% in adults

Milk and egg: based on data within and obtained outside the United States, this rate is likely to be 1-2% for young children and 0.2-0.4% in the general population

Among children with food allergies:

38.7% have a history of severe reactions

30.4% have multiple food allergies

(Gupta RS, Springston EE, et al., 2011)

Policies and Guidelines

There are many laws and guidelines affecting the management of students with life-threatening food allergies at both the federal and state levels.

Students with life-threatening food allergies may qualify for Section 504 plans, for students with disabilities, under the federal Rehabilitation Act of 1973. A 504 Plan is a contract between a school and a student. Having a 504 plan in place is particularly important when any concerns exist with regard to effective food allergy management, such as lack of a full time nurse, limited school resources, or lack of effective policies and procedures. The 504 Plan takes its name from Section 504 of the Rehabilitation Act of 1973, a federal law that prohibits schools that receive federal funding from excluding or otherwise discriminating against a student with a "disability" solely on the basis of that disability. A "disability" under Section 504 is defined by the Americans with Disabilities Amendments Act (ADAA) as a "physical or mental impairment, which substantially limits one or more major life activities." A "major life activity" includes walking, seeing, hearing, speaking, breathing, learning, working as well as eating (U.S Department of Justice, ADAA of 1990, as amended, 42 U.S.C. Section 12101).

Public elementary and secondary educational programs are required to provide a free appropriate public education (FAPE) to qualified students with disabilities. Such an education consists of regular or special education and related aids and services designed to meet the individual educational needs of students with disabilities as adequately as the needs of students without disabilities are met. This includes nonacademic and extracurricular services and activities, including meals, recess periods, and before- and after-school activities¹.

In the case of severely food allergic students, a FAPE usually includes the provision of "related aids and services" such as administration of medication, changes to the classroom environment, menu substitutions, or other health-related needs that require attention during the school day. In order for a student to obtain a 504 plan, the child first needs to be evaluated for eligibility by the school as meeting the definition of "disabled" Parents can request in writing that their child be evaluated for eligibility under the process defined by Section 504. To assist in the evaluation process the school will undertake, parents should be prepared to provide documentation from the child's doctor to the school to support the assertion that the child's food allergies cause a substantial limitation of a major life activity. A 504 Plan is a legally binding document that offers procedural due process safeguards, including due process hearings (with representation legal counsel, if so desired) and parental notice and review requirements. Ultimately, if a parent continues to be dissatisfied with the plan as implemented by the school district, s/he can seek redress with the Office of Civil Rights (U.S. Department of Education), and beyond that, with the federal courts. All public schools are covered by Section 504.

Several federally assisted meal programs, including the National School Lunch Program and School Breakfast Program, operate in public and nonprofit private schools and residential child care institutions. The U.S. Department of Agriculture (USDA) provides funding for these low-cost or free meals to children and implements the nutritional standards based on the Healthy, Hunger Free Kids Act. Any meals prepared in schools receiving Federal funding for school meals, must adhere to USDA standards. In such schools, accommodations for special dietary needs must also fulfill the USDA standards.

The USDA published guidelines, *Accommodating Children with Special Dietary Needs*, in 1995, and minor revisions were made in 2001. Since that time, significant changes have occurred in relevant laws affecting this document, and as of October 7, 2016, the USDA's published guidelines were being revised to incorporate more current versions of Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and the Individuals with Disabilities Education Act (IDEA).

An analysis of Connecticut's policies by the National Boards of Education indicates that Connecticut has one of the nation's most comprehensive sets of policies on anaphylaxis, including the following:

- C.G.S. 10-212a Administration of Medications in Schools
- Section (d) of C.G.S. 10-212a Administration of Medications in Schools by a paraprofessional
- The Regulations of Connecticut State Agencies Section 10-212a-1 through 10-212a-10 Administration of Medications by School Personnel and Administration of Medication During Before- and After-School Programs and School Readiness Programs
- C.G.S. 10-220i Transportation of Students carrying cartridge injectors
- C.G.S. 52-557b Good Samaritan Law
- Section (a) (5) C.G.S. 10-220a In-service training. Professional development committees. Institutes for educators. Cooperating teacher program, regulations

Additionally, according to the Asthma and Allergy Foundation of America (AAFA), Connecticut is one of fourteen states on the 2016 State Honor Roll of Asthma and Allergy Policies for Schools. The recognition is based on a ranking of the states with the best public policies for people with asthma, food allergies, anaphylaxis and related allergic diseases in U.S. elementary, middle and high schools. Connecticut meets all twenty-three of AAFA's core policy standards and meets nine of thirteen of the "extra credit" indicators.

However, despite these high rankings and comprehensive policies, the Task Force found that the efficacy of distribution, implementation and enforcement of these policies and guidelines is inconsistent across school districts in Connecticut and therefore in need of improvement.

Survey Results

The Connecticut Association of Public School Superintendents assisted the Task Force in collecting information about the implementation of current CDSE Food Allergy Guidelines, as well as current transportation protocols as they apply to students with life-threatening food allergies.

165 members of CAPSS were emailed a survey, of which 68 were completed (41%). In addition, an addendum to the survey was distributed to 165 CAPSS members requesting further clarification regarding transportation. 13 members completed the addendum for a response of 8% (see section on Transportation for additional discussion).

An important question was answered by the respondents in concert with the charge of this Task Force: **What specific strategies/protocols do you use to protect students with food allergies in your district?** Only 53% of the respondents answered that the district-wide food allergy plan is published on their public website; 32% publish the plan on their internal websites, and 45.6% provide annual notice of the plan to parents and guardians. It is important to note that CGS 10-212c requires that: 1) a plan be available on a district's web site or the web site of each school, or if such web sites do not exist, that the plan be publicly available through other practicable means; and (2) notice of such plan be provided in conjunction with the annual written statement provided to parents and guardians as required by subsection (b) of section 10-231c "Pesticide applications at schools without an integrated pest management plan.

The Association of School Nurses of Connecticut (ASNC) also helped the Task Force with a survey sent to school nurses throughout the state. The results are summarized in the Plans, Guidelines and Management in Schools section of the report.

Note: The complete CAPSS and ASNC survey results are available in Appendices A and B of this report for reference.

Public Comment

Public comments, received throughout the work of the Task Force, indicate that even though districts are mandated to address certain requirements, there are instances where parents and guardians of students with food allergies do not feel that students' needs are being addressed and appropriate accommodations are not being met. Additionally, several professionals who wrote to the Task Force raised issues for consideration.

References

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

Liu AH, Jaramillo R, Sicherer SH, Wood RA, Bock SA, Burks AW, Massing M, Cohn RD, Zeldin DC (2010). National prevalence and risk factors for food allergy and relationship to asthma: results from the National Health and Nutrition Examination Survey 2005-2006. *J Allergy Clin Immunol.* *126*(4):798-806.e13.

Sampson HA, Mendelson L, Rosen JP (1992). Fatal and near-fatal anaphylactic reactions to food in children and adolescents. *N Engl J Med.*,*327*(6), 380-4.

Plans, Guidelines and Management in Schools

- Examination of the efficacy of the implementation, dissemination and enforcement of the guidelines for the management of students with life-threatening food allergies and glycogen storage disease, developed by the Department of Education pursuant to section 10-212c of the general statutes.
- Examination of the plans for the management of students with life-threatening food allergies and glycogen storage disease, implemented by local and regional boards of education pursuant to section 10-212c of the general statutes, to ensure the safety of students with life-threatening food allergies and their inclusion as fully participating members in the school community.

Background

The management of life-threatening food allergies requires vigilance and daily intervention. The fundamental elements of successful food allergy management include:

- 1) Strict avoidance of allergens across all environments, including accidental exposure and cross contamination
- 2) Knowing how to determine what foods are safe for consumption
- 3) Consistent and immediate access to epinephrine
- 4) Prompt administration of epinephrine at onset of symptoms or in the case of known exposure

In June 2005, PA 05-104 was passed by the Connecticut State Legislature requiring the CSDE to develop guidelines for the management of students with life-threatening food allergies and to have these guidelines available by January 01, 2006. It also required each local and regional board of education, by July 1, 2006, to implement a plan based on these guidelines for the management of students with life-threatening food allergies enrolled in the schools under its jurisdiction, which includes the development of an individualized health care plan for every student with life-threatening food allergies. This was the first attempt to establish standards of care for students with life-threatening food allergies and provide operational guidance to Connecticut school districts. Over the past 10 years, food allergy management has evolved to the point where an update to reflect advances in the standard of care and integrate more recent relevant legislation is warranted. Subsequent sections of this report will cite gap analysis support based on publications by national health and educational organizations, as well as 2016 survey data obtained by this Task Force. CGS § 10-212c houses this act and was updated in 2012 to integrate Glycogen Storage Disease (GSD) in accordance with PA 12-198 (HB5348).

Plans, Guidelines and Management in Schools

Much has changed in the past decade with regard to food allergies, most notably the prevalence. The current guidelines were first introduced when most schools likely had at least one or more students with a life-threatening food allergy. According to the CDC (2013) food allergy among children increased by 50% between 1997 and 2011. The health, safety, and educational implications of these growing numbers can be a challenging issue for schools.

Since 2006 there have been multiple national organizations that have published updated clinical guidelines and standards of care for children with life-threatening food allergies that specifically address their safety and inclusion in school. These organizations include FARE (Food Allergy Research and Education), FAACT (Food Allergy & Anaphylaxis Connection Team), St. Louis Children's Hospital's FAME Program (Food Allergy Management and Education), National School Boards Association's (NSBA) Safe at School and Ready to Learn Program, and the National Association of State Boards of Education's Anaphylaxis Policy Handbook for CT, among others. This presents us with the opportunity to strengthen guidance for CT schools that reflects practices and recommendations by these expert organizations to further promote the safety and inclusion of students with life-threatening food allergies. Additionally, Public Act 14-176, AN ACT CONCERNING THE STORAGE AND ADMINISTRATION OF EPINEPHRINE AT PUBLIC SCHOOLS was passed in 2014. The intent of this landmark legislation was to ensure that no CT student dies of anaphylaxis due to lack of access to epinephrine. Hence schools are required to stock the appropriate dose of epinephrine cartridge injectors (the most common brand being Epipen), and, in the absence of a school nurse, to have at least one qualified school employee trained to recognize and treat anaphylaxis with the stock epinephrine for any student who does not have a prior written authorization signed by a qualified medical provider. Since this law was passed after the latest revision of the CSDE guidelines, they do not include information or provide operational guidance related to it. The CSDE has since developed and made available the annual training for school nurses and school nurse supervisors to provide training to qualified school employees identified within their district.

In 2015 the issue of food allergy management in schools was brought forward to the Education Committee and the full State Legislature. As a result SA 15-17 Sec. 1 was amended by PA 15-242 Sec.53 Section 1. (Effective from passage) to establish a task force to study life-threatening food allergies in schools. Legislative co-sponsor of the task force bill, Representative Brenda Kupchick (R-Fairfield) stated "What I learned from my many meetings, calls, and emails, with parents, school administrators and BOE members over the last two years, was that while the state has good guidelines, each town appears to be doing their own thing, many creating policies that are in direct conflict with CDC guidelines. The issue has created an unfortunate emotional divide between parents of children with life-threatening food allergies and school administrators, staff and parents of students without allergies. After exhausting so many avenues over the last year and trying to get guidance and assistance from the State Department of Education, the State Department of Public Health, Fairfield's administration and Board of Education on this issue, it became clear to me that CT should create a uniform policy for all

school districts, I believe this would ease the emotional divide and protect Connecticut children with life-threatening food allergies.”

In her presentation to the Task Force, Attorney Laurel Francoeur from the Allergy Law Project discussed examples of litigation related to conflict between parents and districts over accommodations for food allergy and other health conditions. She emphasized the importance of promoting collaborative relationships during the Section 504 process in order to avoid contention with its risk for litigation. One of her recommendations based on Connecticut cases included amending the Connecticut guidelines to say that all students with life-threatening food allergies be evaluated for 504 plans.

In an effort to support an accurate and timely needs assessment, the Task Force created and distributed a school nurse and a superintendent survey in partnership with the Association of School Nurses of Connecticut (ASNC) and the Connecticut Association of Public School Superintendents (CAPSS). Both surveys demonstrated aspects to the current guidelines that are not being implemented consistently by districts/schools. This is further supported by many of the public comments that highlight significant concern by parents for the safety and inclusion of their children with life-threatening food allergies during the course of their educational experience. Of the responding districts, 50% of schools in some regions do not post a district plan for the prevention and management of food allergy, and for those that have a plan, it is not always followed consistently throughout a district, or within a school. The superintendents who met with the Task Force also highlighted variations in how district plans are being implemented.

A move toward the development of a standardized food allergy management plan that would address the majority of the priority areas addressed in this report, to be implemented with consistency across all CT school districts, pre-K through grade 12 would go a long way toward easing the burden on school administrators, staff and school nurses, as well as families of food allergic students.

CT Legislation Specific to Life-Threatening Food Allergy Management in School

CGS §10-212(c) a) Not later than July 1, 2012, the Department of Education, in conjunction with the Department of Public Health, shall develop and make available to each local and regional board of education guidelines for the management of students with life-threatening food allergies and glycogen storage disease. The guidelines shall include, but need not be limited to: (1) Education and training for school personnel on the management of students with life-threatening food allergies and glycogen storage disease, including training related to the administration of medication with a cartridge injector pursuant to subsection (d) of section 10-212a, and the provision of food or dietary supplements, (2) procedures for responding to life-threatening allergic reactions to food, (3) a process for the development of individualized health care and food allergy action plans for every student with a life-threatening food allergy,

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(4) a process for the development of individualized health care and glycogen storage disease action plans for every student with glycogen storage disease and such plan shall include, but not be limited to, the provision of food or dietary supplements by the school nurse, or any school employee approved by the school nurse, to a student with glycogen storage disease provided such plan shall not prohibit a parent or guardian, or a person designated by such parent or guardian, to provide food or dietary supplements to a student with glycogen storage disease on school grounds during the school day, and (5) protocols to prevent exposure to food allergens.

(b) Not later than August 15, 2012, each local and regional board of education shall: (1) Implement a plan based on the guidelines developed pursuant to subsection (a) of this section for the management of students with life-threatening food allergies and glycogen storage disease enrolled in the schools under its jurisdiction; (2) make such plan available on such board's web site or the web site of each school under such board's jurisdiction, or if such web sites do not exist, make such plan publicly available through other practicable means as determined by such board; and (3) provide notice of such plan in conjunction with the annual written statement provided to parents and guardians as required by subsection (b) of section 10-231c. The superintendent of schools for each school district shall annually attest to the Department of Education that such school district is implementing such plan in accordance with the provisions of this section.

CGS § 10-212a of the 2014 supplement to the general statutes is repealed and the following is substituted in lieu thereof (*Effective July 1, 2014*): (2) A school nurse or, in the absence of a school nurse, a qualified school employee shall maintain epinephrine in cartridge injectors for the purpose of emergency first aid to students who experience allergic reactions and do not have a prior written authorization of a parent or guardian or a prior written order of a qualified medical professional for the administration of epinephrine. A school nurse or a school principal shall select qualified school employees to administer such epinephrine under this subdivision, and there shall be at least one such qualified school employee on the grounds of the school during regular school hours in the absence of a school nurse. A school nurse or, in the absence of such school nurse, such qualified school employee may administer such epinephrine under this subdivision, provided such administration of epinephrine is in accordance with policies and procedures adopted pursuant to subsection (a) of this section. Such administration of epinephrine by a qualified school employee shall be limited to situations when the school nurse is absent or unavailable. No qualified school employee shall administer such epinephrine under this subdivision unless such qualified school employee annually completes the training program described in section 2 of this act. The parent or guardian of a student may submit, in writing, to the school nurse and school medical advisor, if any, that epinephrine shall not be administered to such student under this subdivision.

Sec. 2. (*Effective July 1, 2014*) Not later than December 31, 2014, the Departments of Education and Public Health shall jointly develop, in consultation with the School Nurse Advisory Council, established pursuant to section 10-212f of the general statutes, an annual training program regarding emergency first aid to students who experience allergic reactions. Such annual training program shall include instruction in (1) cardiopulmonary resuscitation, (2) first aid, (3) food allergies, (4) the signs and symptoms of anaphylaxis, (5) prevention and risk-reduction strategies regarding allergic reactions, (6) emergency management and administration of epinephrine, (7) follow-up and reporting procedures after a student has experienced an allergic reaction, (8) carrying out the provisions of subdivision (2) of subsection (d) of section 10-212a of the general statutes, as amended by this act, and (9) any other relevant issues and topics related to emergency first aid to students who experience allergic reactions. The Department of Education shall make such annual training program available to local and regional boards of education.

I. Efficacy of Distribution of CSDE Guidelines

A manual was printed and distributed for school districts after the initial publication of the guidelines in 2006. In 2012 the guidelines were updated to integrate Glycogen Storage Disease. This revision was posted on the CSDE website and is currently available at <http://www.sde.ct.gov/sde/cwp/view.asp?a=2663&q=334632>. Several school superintendents attested to the gap in dissemination of the CSDE guidelines during discussion at the November 17th Task Force meeting. They stated that the current turnover rates for school administrators and superintendents and the hiring of those from outside of the state of Connecticut has contributed to this gap in awareness of the guidelines.

II. Efficacy of Implementation of CSDE Guidelines

As stated in the CSDE Guidelines, the goals of a district-wide management plan are to 1) maintain the health and safety of children with life-threatening food allergies in ways that are developmentally appropriate, promote self-advocacy and competence in self-care and provide appropriate educational opportunities (FAPE), 2) Ensure interventions and individual health care plans are based on medically accurate information and evidence based practice and 3) to define a formal process for identifying, managing, and ensuring continuity of care across all transitions (pre-K to 12).

In order to understand the efficacy of implementation of the CSDE Guidelines, the Task Force used this lens and looked at sample district policies provided by CAFE, initiated and reviewed surveys of district superintendents and school nurses, heard expert testimony on school climate, legal requirements and application, and school transportation practices, and solicited written comment from parents and other interested parties. It became apparent to the Task

Force that there are various complex and, in some cases, controversial aspects to safe and inclusive food allergy management in school.

Food allergy management must include emergency response practices as well as proactive and collaborative prevention practices, i.e. allergen awareness and avoidance in a climate of acceptance. While emergency care plans and access to and the administration of life-saving epinephrine is vital for the ultimate safety of food allergic students who experience anaphylaxis, emergency response means that the protection of the student with known allergies has somehow failed – every allergy exposure to the food allergic child is potentially avoidable. The implicit intent of both the state and the CDC guidelines alike was to shift the paradigm from emergency response to prevention. The importance of this cannot be overlooked, as it is not only an anaphylactic emergency that impacts a student. Any suspected allergic response removes the student from their education, as it requires evaluation, monitoring, potential treatment, and undermines a student’s ability to feel safe at school and therefore ready and able to learn.

After reviewing extensive data from the Task Force surveys, including hundreds of comments, and the many public comments submitted, it becomes evident that there are districts and individual schools that have taken the initiative to implement and update their allergy management plans to reflect current standards of care and exemplary procedures to promote the safety and inclusion of students with life-threatening food allergy in their schools. These districts have modeled practices such as: not serving or selling peanut or tree nut products; not using food for class celebrations or rewards, comprehensive training of food service staff and teaching staff; providing 504 plans to all students with life-threatening food allergy; and field trip options based on the risk to students with life-threatening food allergies.

It should be noted that, while the CSDE collects information about the number of students receiving epinephrine as a result of an allergic reaction to a food through its Health Services Program Information Survey (82% of districts participated in 2015), there is currently no mandate that school districts collect or report data on allergic reactions that requires administration of epinephrine and subsequent transport to a hospital emergency room,

School Nutrition Programs

An area of vital importance in the daily management of food allergic students, and in the interests of school districts to remain in compliance with federal law, is access to school nutrition programs funded by the United States Department of Agriculture. USDA regulations require the accommodation of students with special dietary needs so as to ensure non-discrimination. Upon presentation of a special diet order form signed by a licensed physician, a school food service provider (whether district managed or outsourced to a vendor) is required to make accommodations for that student. Neither the USDA Food and Nutrition Service (FNS) nor the CSDE have explicit guidance about what constitutes reasonable accommodation. It is the responsibility of the schools and school food authorities to establish appropriate reasonable

accommodations, and what is reasonable for one school district may not be the case for another. Ultimately, the school has the responsibility to provide a safe, non-allergic meal to the child if it is determined that the condition is disabling. To do so, school food service staff must make sure that all food items offered to the allergic child meet prescribed guidelines and are free of foods that are suspected of causing the allergic reaction. This means that the food labels or specifications will need to be checked to ensure that they do not contain traces of such substances. In some cases, the labels will provide enough information to make a reasonable judgment possible. If they do not provide enough information, it is the responsibility of the school food service to obtain the necessary information to ensure that no allergic substances are present in the foods served.

Contributing to the difficulty of meeting these requirements is the currently unregulated use of the “may contain” or “produced on equipment that processes [allergen].” The Food Allergen Labeling and Consumer Protection Act (2004) labeling requirements do not apply to the potential or unintentional presence of major food allergens in foods resulting from “cross-contact” situations during manufacturing, e.g., because of shared equipment or processing lines. In the context of food allergens, “cross-contact” occurs when a residue or trace amount of an allergenic food becomes incorporated into another food not intended to contain it. FDA guidance for the food industry states that food allergen advisory statements, e.g., “may contain [allergen]” or “produced in a facility that also uses [allergen]” should not be used as a substitute for adhering to current good manufacturing practices and must be truthful and not misleading. However, there is currently no regulation of this type of labeling, and while labeling can warn about the presence of an unintentional allergen, precautionary allergen labels bear no relationship to actual risk, leaving it to the school food service provider to determine what the label actually means – often by contacting the manufacturer directly.

Providing families with updated, accurate information about food ingredients and processing is largely dependent on the district food service staff being able to effectively read and research food labels and communicate menu options and changes in food offerings that may pose risks.

Under the new USDA Final Rule: Professional Standards for State and Local School Nutrition Programs as Required by the Healthy, Hunger-Free Kids Act of 2010, training standards including minimum number of hours of annual training are required for both food service directors and all school food service personnel. However, there are no specific requirements for training for preparing food for food allergic students. According to one food service provider in Connecticut, their staff receives 1 hour of training in food allergens per year. Given the recommendations from the recent study from the National Academies of Sciences, Engineering and Medicine (Finding a Path to Safety in Food Allergy: Assessment of the Global Burden, Causes, Prevention, Management, and Public Policy, 2016), training of food service staff is an important piece of preventing food allergic reactions and should be required of all food service staff.

Strict avoidance of allergens by the food allergic student across all environments is the fundamental and crucial element to food allergy management, and must be adhered to during school hours.

Access to the educational environment and school-based programs is another area of deficit that is not well addressed by the guidelines. PTA/PTOs also may not create events that are safe for food allergic children and therefore restrict their access. The Office of Civil Rights (OCR) has addressed several of these issues in Dear Colleague letters explaining that school based programs are an extension of the school day and therefore must provide for safe and equal access. During the school day, as well as during extracurricular and other school sponsored activities and events (PTA/PTO and other outside groups supported by schools), the management of a child's life-threatening food allergies becomes a shared responsibility, shifting from parent to school staff. According to the 2014 CSDE Field Trips: Guidance for school nurses – "School nurses may provide information to the facilitators of extracurricular school-sponsored trips regarding the legal requirements for medication administration and nursing care to students during extracurricular activities and help the facilitators determine best practices for the health and safety of students during these activities; however, school nurses cannot legally delegate nursing care or medication administration for extracurricular activities."

Differences related to growth in maturity and developmental abilities that will empower a student to take on more responsibility for the management of their allergies as they age-up should be considered. It is important to define what appropriate self-management should look like, particularly for middle and high school students, as evidence suggests that middle and high school students are routinely overlooked when it comes to school based food allergy management support and protections. Indeed, testimony by the superintendents before the Task Force stated that most supports for students with life-threatening food allergies fall away as they age up. Food allergic teens are at the highest risk of death from anaphylaxis (Sampson, Mendelson, et. al. 1992). Changes in physiology, nature of the food allergy (peanut and tree nut and shellfish allergies tend to be lifelong, whereas many outgrow dairy and egg allergy by adolescence), less supervision by adults, risk taking behavior associated with normal adolescent development and compounded by feeling different due to their allergies and seeking social normalcy, shifts in types of socialization (dating) and other factors all contribute to increased risk of severe allergic reactions in teens. Therefore, students in middle and high school require accommodation and support, but with a shift of focus. Food allergy self-management for a teenager involves the following: knowing not to eat foods that may be unsafe, always carrying their epinephrine, alerting an adult or peer if they have had exposure to an allergen or are having symptoms, and knowing how to self-inject their life-saving medication (though they may be rendered unable to do so during anaphylaxis). It does not mean that any student should have to police their peers or staff, or be responsible for the enforcement of preventive protocols meant to prevent reactions. To make students responsible for those things can create hostility, highlight their medical disability (compromise their privacy) and can lead to harassment/bullying and have a negative impact on inclusion, which in turn results in increased

anxiety, and reduced willingness to implement self-care. It is important to remember that each student is an individual and accommodations must be made on an individual basis. Therefore, the implementation of district-wide food allergy management plans, coupled with individualized 504 accommodation plans, Individualized Health Care Plans and Emergency Care Plans will provide the necessary safety while integrating all of the essential considerations that ensure inclusion.

III. Efficacy of Enforcement of CSDE Guidelines

There is no clear mechanism for enforcement of the creation, implementation, or website posting of the CSDE guidelines. The CSDE does require that superintendents of schools submit a signed affidavit attesting compliance with the state statute, but the accuracy of this self-reporting appears insufficient, as substantiated by the Task Force's survey data.

School districts should be evaluating the effectiveness of their allergy plans and policies on an annual basis, reviewing with key members of their allergy plan team, and implement improvements as indicated. The team should also be debriefing after each emergency event to identify contributing factors and address the ones that are avoidable, i.e. eating on the bus, cross contamination in the classroom, or food sharing in the cafeteria.

CT Specific Data

The CSDE distributes a voluntary school health services survey each year to district nursing supervisors (or those functioning in that role). Eighty two percent of districts completed the survey for the school year 2014-2015, representing 408,407 public school students. The districts that participated identified 14,315 students with known life-threatening food allergy. Forty one percent of districts administered epinephrine at least once during that school year.

This data does not reflect whether or not districts have implemented a plan in accordance with this legislation, nor does it indicate the scope of any district's plan, e.g. cafeteria/food service protocols, classroom celebrations, eating, and activities, transportation, before and after school programs, and field trips. As such, the Task Force collaborated with CAPSS and ASNC to create and distribute a survey to each target group (superintendents and school nurses) to gather and analyze relevant data that reflects current practice, values, and beliefs.

School Nurse Survey

Out of the 474 school nurses who started the survey, 371 completed it, each representing a CT school, for a total of 7659 students with a known life-threatening food allergy. Elementary schools represented 50% of the survey. Twenty three percent of schools reported administering

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at least one dose of epinephrine to treat anaphylaxis during the previous school year, with 8% of schools reporting that they administered 3 or more doses. Twenty percent of schools reported that less than 50% of students with a known life-threatening food allergy have their own supply of epinephrine in school, and 25% reported that less than 50% of those students have an IHCP for their food allergy. Seventy percent reported that less than 10% of those students have a 504 plan for their food allergy. More than 40% of school reported that at least half their emergency allergy plans ordered the use of Benadryl before epinephrine, which is clearly contraindicated by a number of national standard of care publications. This is primarily an issue with the medical community that would require a collaborative approach to address. Additionally, 12% of schools do not have stock epinephrine available; 11% do not have a staff member trained to recognize and treat anaphylaxis if the nurse is not available; and up to 20% of schools do not have or implement a district food allergy plan. Lastly, 78% of nurses indicated that the parental/guardian opt-out for epinephrine jeopardizes student safety, with nearly 15% “not sure”, indicating that not all school nurses are aware of the opt-out option for parents. The opt-out option means that a parent can opt-out of their child getting epinephrine for anaphylaxis for an unknown allergy causing a reaction for the first time in school. The leading risk factor for dying from anaphylaxis is a delay in the administration of epinephrine. There has been reported confusion regarding parent/guardian understanding of what the ramification of the opt-out authorization and there is no practical way to identify students whose parents chose the opt-out during an acute, potential medical emergency.

Table 1. Survey data by county

County	# of schools reporting	# Students with a known LTFA for this *SY	# Medication authorizations for epinephrine (%)	# Emergency Allergy Plans (%)	% of schools with stock epi	% of schools with 1 or more trained staff**	# schools with district food allergy prevention & management plan
Hartford	92	1967	1482 (75%)	1096 (56%)	74%	88%	77%
Middlesex	16	247	226 (91%)	173 (70%)	94%	94%	50%
New London	30	356	313 (88%)	271 (76%)	90%	69%	79%
New Haven	108	2178	1755 (81%)	1428 (65%)	86%	91%	77%
Fairfield	87	2555	2378 (93%)	2223 (87%)	97%	95%	92%
Litchfield	14	52	47 (90%)	33 (63%)	100%	86%	50%
Windham	14	135	125 (93%)	82 (60%)	93%	86%	100%
Tolland	10	169	128 (76%)	105 (62%)	100%	80%	100%
Totals	371	7659	6454 (84%)	5411 (71%)	87%	89%	80%
				Average			

*SY: 2016-17 School Year

** Staff trained to recognize anaphylaxis and administer epinephrine auto-injector to any student

Table 2. Main themes from open-ended questions

What are your biggest challenges to ensuring the safety and inclusion of students with LTFA? N= 282	Do you have any best practices that you would like to highlight? N = 164	Any other comments that you would like to share? N = 91
Inconsistency with implementation of peanut/tree nut restrictions between classrooms, cafeteria, and field trips	Communicating to staff, including subs, about individual’s food allergies	Working with administration to promote non-food celebrations
Parents or staff bringing in food for celebrations (by far,	Minimizing food used in classroom	Can’t force students to eat at allergy free tables

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the most common comment)		
Teachers using food as a reward	Promoting hand washing	
Food sharing	Food service listing allergy ingredients and carbs on menu (not just peanut/tree nuts)	Have a nut free food service
Staff education	Ongoing education with students and staff	Need a standard emergency plan that integrates the med authorization
Food service staff prepared to monitor food labels	Cafeteria staff entering allergy information into cash register/computer	Promote “allergy aware zones” rather than “peanut free”
Price/affordability of Epi pens for parents	Peanut and nut free tables	The cost of Epi pens
Communication and clarifications from parents and providers about allergies and obtaining emergency plans	District sending letter home to all families about food allergy safety	Need more consistency getting forms signed by providers and parents
Students not taking their allergy seriously, not carrying epinephrine	Having IHCPs on all students with food allergies	504s are a work in progress
Activities that do not promote inclusion for students	Having a Nut table for students who bring that in for lunch	

Challenge excerpts:

“School parties create the biggest challenge to keeping students safe, especially in the elementary schools. The time and energy it takes to ensure that no harmful foods are brought into the classroom is exorbitant”

“Educating parents of children without life-threatening allergies of the seriousness of the issue and need for policies in school”

“Prevention of students sharing food and bringing in food that others are allergic to”

Best practice excerpt:

“We have a very specific snack list that we are very strict about: if a person is to bring outside food into school to share (i.e. group snack in lower grades) it must come from the list or it is not allowed. We also changed to NON-food celebrations. Teachers are not supposed to celebrate with food or to reward with food. This takes some time for the teachers to get used to (like 6

months) but in the end it makes their job so much easier rather than having to police foods in class.”

IV. Gap Analysis:

An evaluation of the efficacy of the dissemination, implementation and enforcement of the CSDE guidelines would be incomplete without a detailed review of the content value of the guidelines themselves. In October of 2013, the Centers for Disease Control published “Voluntary Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs” as a means to support the implementation of school-based food allergy management plans and improve existing practices. In review of the CDC Guidelines, the Task Force was able to ascertain that the CT Guidelines need to be updated to reflect current standards of care, best practices and address particular crucial domains of food allergy management.

The CDC Guidelines focus on the following areas:

- 1) “Essential practices for protecting children from allergic reactions that occur in schools”
- 2) “Develop strategies to reduce risk of exposure to food allergens in classrooms, cafeterias, and other school settings”
- 3) “Emphasize training for staff to improve their understanding of food allergies, their ability to help children prevent exposure to food allergens, and their ability to respond to food allergy emergencies (including the administration of epinephrine). This training can help to create an environment of acceptance and support for children with food allergies.”
- 4) “Emphasize the need to teach children about food allergies as part of the school’s health education curriculum”
- 5) “Address the need to teach all parents about food allergies”
- 6) “Address the physical safety and emotional needs of children with food allergies (i.e. stigma, bullying, harassment)”
- 7) “Include a list of actions for all staff working in schools that may have a role in managing risk of food allergy”

In addition, the CDC Guidelines highlight five priority areas that should be addressed within each school’s Food Allergy Management Prevention Plan:

- 1) Ensure the daily management of food allergies in individual children
- 2) Prepare for food allergy emergencies
- 3) Provide professional development on food allergies for staff members
- 4) Educate children and family members about food allergies
- 5) Create and maintain a healthy and safe educational environment.

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The key takeaways from the CDC Guidelines that must be integrated into the CT Guidelines are:

- 1) The shift in focus from emergency response to preventive practices
- 2) Identifying staff responsibilities and enabling them to positively impact the daily management of a student’s food allergies, as well as emergency response
- 3) The importance of education on this chronic and potentially fatal health condition for the entire school community from administrators down to families of non-allergic children.
- 4) The importance of creating an inclusive, understanding and supportive school climate to improve physical, educational, social and emotional outcomes for food allergic students throughout their entire educational career.

CDC Guidelines	CSDE Guidelines
About Food Allergies <ul style="list-style-type: none"> • Section is clear and comprehensive 	Would need to integrate stock epinephrine and staff training language
Section 1 Priorities for Managing Food Allergies <ul style="list-style-type: none"> • Part 1. Daily Management • Integrates USDA, 504, IEP, and IHP 	Not cohesively addressed
<ul style="list-style-type: none"> • Part 2. Preparing for a food allergy emergency 	Not included
<ul style="list-style-type: none"> • Part 3. Provide professional development for staff <ul style="list-style-type: none"> ○ Provide general training for all staff, and increasing levels of training as indicated 	Not included
<ul style="list-style-type: none"> • Part 4. <ul style="list-style-type: none"> ○ Teach all children about food allergies ○ Teach all parents and families about food allergies 	Not included
<ul style="list-style-type: none"> • Part 5. Create a healthy and safe educational environment 	Not specifically addressed
Food allergy management and prevention checklist	No included
Many examples of roles and responsibilities	Included, not as extensive
Not included	Included appendices with examples of emergency care plan and IHCPs – need update to reflect current best practice
Current Standard of Care (see references)	
Both clearly identify epinephrine as the first-line medication for any suspected anaphylaxis	Not included
Both differentiate treatment of allergy and anaphylaxis from medical centers and schools	Not differentiated

References

Guidelines for the diagnosis and management of food allergy in the United States: Summary of the National Institute of Allergy and Infectious Diseases (NIAID)-Sponsored Expert Panel Report (2010) <http://www.foodallergy.org/file/niaid-clinician-summary.pdf>

Anaphylaxis and Schools: Developing policies for treating students with severe allergic reactions (2013). National Association of State Boards of Education. http://www.nasbe.org/wp-content/uploads/Anaphylaxis-Discussion-Guide_10-30-13.pdf

Voluntary guidelines for managing food allergies in schools and early care and education programs (2013). Center for Disease Control and Prevention. http://www.cdc.gov/healthyyouth/foodallergies/pdf/13_243135_a_food_allergy_web_508.pdf

Pistiner, M., and Devore, C.D. (2013). The Role of pediatricians in school food allergy management. *Pediatric Annals*, 42:8

Food allergy and anaphylaxis toolkit. National Association of School Nurses. Accessed December 2, 2016. <http://www.nasn.org/toolsresources/foodallergyandanaphylaxis>

Anaphylaxis in the E.D A reference for physicians

http://college.acaai.org/sites/default/files/Resources/151010_anaphylaxis_flyer.pdf

Sampson HA, Mendelson L, Rosen JP (1992). Fatal and near-fatal anaphylactic reactions to food in children and adolescents. *N Engl J Med.*, 327(6), 380-4.

Transportation of Students with Life-Threatening Food Allergies

- Examination of methods used by school districts to ensure the safety of students with life-threatening food allergies while such students are being transported to and from school.

I. Current regulations, guidelines and policies

A. Federal Law

Certain federal laws pertain to the school districts' responsibility for meeting the needs of safety of students with life-threatening food allergies (Americans with Disabilities Act, Individuals with Disabilities Education Act of 1976, The Family Education Rights and Privacy Act of 1974, and The Rehabilitation Act of 1973 (Section 504).

B. Connecticut State Law

Legislators are referred to the attached sections of the Connecticut General Statutes 2015 which reviews life-threatening food allergies: Section 10-212a-g, Section 10-220i, and Section 52-557b. There is presently no language that includes school transportation or the training of transportation personnel in any of the referenced state statutes. Upon extensive research and expert presentations, the Task Force recommends the training of transportation personnel in the symptoms of anaphylaxis and the administration of epinephrine to an identified student experiencing anaphylaxis during transportation. Upon passage, the language may need to be changed to include transportation personnel.

C. Connecticut State Department of Education

The Guidelines for Managing Life-threatening Food Allergies and Glycogen Storage Disease (Revised, 2012). Section 4 (pages 25, 27) references transportation; and Appendix A specifically provides the current guideline (not mandate) for transportation companies to follow:

Suggested Roles and Responsibilities: School Bus Company

Provide education for all school bus drivers regarding life-threatening allergies (provide own training or contract with school) and what to do if they suspect a student is having a reaction. Provide education for school bus drivers on specific children, when appropriate. Provide functioning emergency communication device (e.g., cell phone, two-way radio, walkie-talkie or similar). Know local Emergency Medical Services procedures. Maintain policy of not allowing foods or beverages to be consumed on school buses. Provide school bus dispatcher with list of students with life-threatening food allergies

by bus/van number and instructions for activating the EMS system Plan ahead for informing substitute bus drivers of students with life-threatening food allergies.

The Task Force heard a presentation by Leslie Sheldon, President of the Connecticut School Transportation Association (COSTA) and Operations Manager of All-Star Transportation. She summarized the current state guidelines and transportation company practices while students with life-threatening food allergies are being transported to/from school or school-sponsored activities: in the majority of districts there is no trained adult (unless the district provides a trained paraprofessional on the vehicle) to administer epinephrine to a student experiencing anaphylaxis. As was outlined, currently the driver is trained to pull the vehicle to the side of the road, secure the vehicle, and call dispatch that would then call 9-1-1 to the location. The current practice leaves students with life-threatening food allergies at great risk for death from anaphylaxis, as the administration of epinephrine is delayed while waiting for first responders to arrive. The Task Force considered the location of vehicles during a potential emergency, with some districts in more rural settings may have longer response times from EMS. Another important consideration is “dead zones” throughout the state where two-way radio or cell phone signals do not come in clearly, if at all.

It is stated in transportation company policy as well as the CSDE guidelines that food consumption is not allowed during transportation. It is important to recognize that a life-threatening allergic reaction may occur on a transportation vehicle as a result of exposure at home before school or during school hours. Allergic reactions may occur within minutes up to four hours after exposure to the allergen. As an example, a student who is exposed to an allergen eating lunch at school at 12pm may board a transportation vehicle at 3pm and start showing signs of a reaction. Additionally, a student who self carries epinephrine may not be able to self-administer the medication depending on the severity of the reaction.

The Task Force recognizes that transportation personnel deal with behavior issues on the bus, potential lack of visibility from mirrors, distracted drivers, and other safety concerns. Like parents, teachers, paraprofessionals, coaches, and other school staff, they are not health care professionals. Training drivers to administer epinephrine to an identified student experiencing anaphylaxis will not add additional burden, but rather provide invaluable education and training so they can respond quickly and appropriately should one of the scenarios outlined above occur while the student is being transported.

D. District Policies

In the CAPSS survey performed by this Task Force, the following results as it pertains to transportation issues revealed the following statistics:

1. 33.82 % of responding school districts require all drivers who transport children to/from school to have training in the signs and symptoms of anaphylaxis and the administration of epinephrine.
2. 15.38 % of responding school districts require all transportation drivers to have training in the administration of epinephrine auto-injectors.
3. 55.88% of responding school districts ensure that drivers who transport children know the identity of the students who have food allergies and which students carry Epinephrine.
4. 47.06% of responding school districts ensure that drivers follow a written plan or protocol for the handling of food allergic emergencies.
5. 85.29% of responding school districts ensure that school transportation vehicles have communication devices in addition to cell phones.
6. 72.06% of responding school districts enforce no-eating rules on transportation vehicles.
7. 54.41% of responding school districts have a risk assessment procedure as part of field trip planning

II. Gap Analysis: between law, recommendations and current practice

A. Federal Law

Safe transport of students with life-threatening food allergies is vital. Any denial of accommodation as outlined in Section I (A) above may constitute discrimination under the ADA, IDEA, and Section 504.

B. Other state laws

Rhode Island and Massachusetts have passed laws to train school transportation drivers in the signs and symptoms of anaphylaxis and the administration of epinephrine. We recommend that the Legislators refer to: the State of Rhode Island General Laws, Title 16, Chapter 16-21, Health and Safety of Pupils, Sections, 16-22 (Attachment A); Commonwealth of Massachusetts General Laws, Title 14, Chapter 90, Section 8A (Attachments B and C).

C. Connecticut State Law

C.G.S. §10-212a-1 through 10-212a-10 Administration of Medication by School Personnel and Administration of Medication During Before-and-After School Programs and School Readiness Programs does NOT include Administration of Medication by Transportation Personnel in the language. **Pending legislation mandating the training in the administration of epinephrine, we recommend amending this statute to include transportation personnel.**

Districts who do not allow a student with life-threatening food allergies to self-carry their epinephrine auto-injector during transportation are in direct violation of **Sec. 10-220i.**

Transportation of students carrying cartridge injectors. No local or regional board of education shall deny a student access to school transportation solely due to such student’s need to carry a cartridge injector while traveling on a vehicle used for school transportation.

C.G.S. 52-557b The Good Samaritan Law will additionally need to apply to transportation personnel upon passage of our recommendation to train drivers to administer epinephrine. The law provides immunity from liability for emergency medical assistance, first aid or medication by injection. This statute provides immunity from civil damages to individuals who have been properly trained and who provide emergency assistance, voluntarily and gratuitously and other than in the course of their employment or practice to another person in need of assistance.

D. Current Practice

Branford Public Schools (BPS) is an example of a school district in Connecticut mandating training in the signs & symptoms of anaphylaxis AND the administration of epinephrine to drivers. The Task Force heard a presentation given by Branford Superintendent of Schools Hamlet Hernandez, and Captain Michael Rebmann of the Branford Fire Department. In 2013 the Board of Education negotiated this training into the contract with First Student (Branford only). Currently, drivers in Branford are trained annually by Captain Rebmann (who is also a paramedic) at no cost to the district. The training is filmed so that new drivers who start with First Student at other times of the year receive the same training. It is the responsibility of First Student (Branford) to implement the training into their existing modules. In their presentations, Superintendent Hernandez and Captain Rebmann discussed the initial resistance the company gave regarding the training; that it was an additional burden to the already over-taxed drivers, that drivers had a fear of doing something wrong, that the training violated their policy of not being able to touch students on their vehicle. They clearly stated that through the training, which included hands-on practice of injection through the use of Epi-Pen trainers, their fears and resistance were alleviated. Captain Rebmann reported feedback that the drivers appreciate the training (in place now for three years), as they will know how to appropriately respond in the event of an anaphylactic emergency.

E. District Policies

Specific to while such students are being transported to and from school, or to school-sponsored activities, it is important to note that a student may have an Individualized Health Care Plan (IHCP) without a 504 plan, and/or authorization from a physician, school nurse, and parent allowing them to self-carry and/or self-administer an epinephrine auto injector. The Task Force received public comment that raised concern:

- despite transportation being defined as part of the school day, some districts are not accommodating students with life-threatening food allergies while being transported to/from school.
- some districts are going against the student's physician orders to self-carry their life-saving medication during transportation.
- some schools do not include an accommodation for transportation as part of a student's 504 plan despite written and verbal requests from parents and physicians.

References:

Bus Drivers and Transportation (2016). Food Allergy & Anaphylaxis Connection Team
http://www.foodallergyawareness.org/education/for_school_personnel-3/bus_drivers_%2B_transportation-5/

Position Statement: Anaphylaxis in schools and other child-care settings, American Academy of Allergy, Asthma and Immunology, J Allergy Clinical Immunology 1998; Vol.102, No. 2, 173-175.

Attachment A

State of Rhode Island General Laws

TITLE 16

Education

CHAPTER 16-21

Health and Safety of Pupils

SECTION 16-21-22

§ 16-21-22 Allergic emergencies – Anaphylaxis – Use of epinephrine – Immunity for those administering. – (a) The department of elementary and secondary education and the department of health shall incorporate into their policies, rules, and regulations pertaining to school health programs a procedure for addressing incidents of anaphylaxis (exaggerated allergic reaction) in order to provide for the health and safety of children who have been medically identified as being prone to anaphylaxis or who show evidence of anaphylaxis. The policies, rules, and regulations shall include a procedure whereby a parent or legal guardian of any child may expressly authorize the school department and school bus drivers and monitors to administer the epinephrine on his or her child in case of an emergency and ensures that the epinephrine is kept in a conspicuous place, readily available and that their proper use is made known to school personnel. School bus drivers and monitors shall receive training in the administration of epinephrine. To treat a case of anaphylaxis, trained school bus drivers and/or monitors shall administer the epinephrine auto-injector to an identified student.

(b) The policies, rules and regulations shall also include a procedure to allow children to carry and use prescription inhalers, and auto-injectable epinephrine, while in school, at a school sanctioned function or event, or in transit to and from school or school sanctioned function or event by the school bus service provider; when prescribed by a licensed individual with prescriptive privileges. Children who need to carry prescription inhalers and/or auto-injectable epinephrine shall provide the school and the school bus service provider with medical documentation that the inhaler and/or auto-injectable epinephrine has been legitimately prescribed and that the child needs to carry it on his or her person due to a medical condition but no child shall be disciplined solely for failure to provide this documentation in advance.

(c) Parents shall provide a doctor's letter or prescription notifying the school and the school bus service provider of their child's allergy and the need to administer epinephrine in an allergic emergency.

(d) No school teacher, school administrator, or school health care personnel, school bus driver, school bus monitor or any other school personnel shall be liable for civil damages which

may result from acts or omissions in use of the epinephrine which may constitute ordinary negligence; nor shall the school personnel mentioned in this subsection be liable for civil damages which may result from acts or omissions in the use of prescription inhalers by children which may constitute ordinary negligence. This immunity does not apply to acts or omissions constituting gross negligence or willful or wanton conduct. For the purposes of determining immunity from liability under subsection (d) only, the term "other school personnel" shall include any private entity providing school bus services and individual school bus drivers and monitors employed or otherwise engaged by such school bus service entities.

(e) School physicians may execute standing orders and prescriptions for school nurses to use epinephrine when there are symptoms of anaphylaxis.

(f) The student's parent or guardian is responsible for supplying and replacing when necessary all prescription medication that is authorized pursuant to this section.

History of Section.

(P.L. 1995, ch. 358, § 1; P.L. 1996, ch. 43, § 1; P.L. 1996, ch. 324, § 1; P.L. 1997, ch. 293, § 1; P.L. 1998, ch. 146, § 1; P.L. 1999, ch. 342, § 1; P.L. 2005, ch. 254, § 1; P.L. 2005, ch. 264, § 1; P.L. 2012, ch. 108, § 1; P.L. 2012, ch. 146, § 1.)

Attachment B

PART I ADMINISTRATION OF THE GOVERNMENT
TITLE XIV PUBLIC WAYS AND WORKS
CHAPTER 90 MOTOR VEHICLES AND AIRCRAFT
Section 8A Operators of school buses; licensing; training; instructors

Section 8A. Application for a license to be a school bus operator may be made by any person who shall have attained the age of eighteen years but who has not passed his seventieth birthday, except as otherwise provided herein, and who shall have been a duly licensed motor vehicle operator for a period of three continuous years immediately prior to his application except a person who has been licensed and whose license is not in force because of revocation or suspension or whose right to operate is suspended by the registrar; but before such person shall be so licensed the registrar shall be satisfied that he is of good moral character and has successfully completed a driving performance test, a visual test, a written test and a physical examination by a licensed physician within a three month period of the date of his application in conformity with such minimum physical qualifications as shall be determined by the registrar; provided, however, that a person who has passed his seventieth birthday and is mentally and physically capable of performing the duties of a school bus operator shall be eligible for a license under this section. Such person shall twice annually, at his own expense, be examined by a physician to determine such capability. Said examination shall not be completed within a six month period of each other and that the first physical examination shall be completed within thirty days prior to the beginning of the school year and the second examination shall not be less than six months nor more than seven months thereafter; provided, further, that no license shall be issued to a person who is a sex offender, as defined in section 178C of chapter 6, or who has been convicted of the use, sale, manufacture or distribution of or possession with intent to distribute any of the controlled substances which are unlawful under the provisions of section thirty-one of chapter ninety-four C, or to any person who has been convicted of operating a motor vehicle while under the influence of intoxicating liquor or of marijuana, narcotic drugs, depressants or stimulant substances, all as defined in section one of said chapter ninety-four C, or of the vapors of glue, within the preceding five year period under the provisions of section twenty-four. Any person who has consented to have any such case disposed of under the provisions of section twenty-four D shall, for the purposes of this section, be deemed to have been convicted.

All original applicants for a registry of motor vehicles school bus driver's license or a department of telecommunications and energy driver's license when used to drive school pupils to or from school shall have first satisfactorily completed a pre-service school bus driver training program established by the commissioner of education in collaboration with the registrar and the commissioner of the department of telecommunications and energy and a basic course in first aid which shall include training relative to the administration of an epinephrine auto injector, as approved by the registrar. Upon successful completion of the first aid course, section 55A of chapter 71 shall apply to such applicants. In addition, all renewal applicants for a registry of motor vehicles school bus driver's

license or a department of telecommunications and energy driver's license when used to drive school pupils to or from school shall have first satisfactorily completed an in-service driver training program established by the commissioner of education in collaboration with the registrar and the commissioner of the department of telecommunications and energy. All original applicants for a registry of motor vehicles school bus driving instructor's certificate shall have first satisfactorily completed an instructor's training program as approved by the registrar. No person shall be employed to provide instruction in any capacity for the operation of school buses unless such person is the holder of such an instructor's certificate issued by the registrar.

Notwithstanding the provisions of section thirty-two G of chapter ninety to the contrary, a person may engage in the business of instructing in pre-service and in-service school bus driver's training programs by being a certified school bus instructor. A private driving school licensed under section thirty-two G may offer pre-service and in-service school bus driver training programs for compensation, provided that such school shall offer said training under the direction of a certified school bus driving instructor.

Applications for a certificate, under this section, may be filed with the registrar and shall contain such information as he shall prescribe. Each such application shall be accompanied by an application fee which in no event shall be refunded. The application fee and an annual fee to maintain said certificate shall be determined by the commissioner of administration under the provision of section three B of chapter seven. No fee or compensation shall be charged in whatever manner to the participants in the pre-service and in-service training courses.

Any such license or special permit or school bus driving instructor's certificate issued under the provisions of this section shall be valid for a period of twelve months from date of issue.

Upon application for a renewal of such license for such instructor's certificate, the registrar shall require evidence of physical fitness and may require evidence of continuing good character.

The registrar may suspend or revoke a license or instructors certificate granted under authority of this section for a violation of any of the provisions of this chapter, or on other reasonable grounds, or where, in his opinion, the licensee or instructor is either physically or morally unfit to retain the same.

The registrar may make such rules and regulations as he may deem necessary to carry out the provisions of this section.

Attachment C

Massachusetts Department of Public Health
Bureau of Family and Community Health
School Health Unit

EPINEPHRINE COMPETENCY SKILL CHECK LIST

Name and Title of Staff Person: _____

The following competencies have been demonstrated by staff person:

States the responsibilities of the school nurse for training and supervision _____

Identifies common causes of allergic emergencies _____

Describes general and student-specific warning signs of allergic emergency _____

Demonstrates how to activate the school's plan for responding to emergencies _____

Identifies student for whom the epinephrine is prescribed _____

Interprets accurately the emergency medication administration plan _____

Follows the directions on the medication administration plan _____

Reads the label on the epinephrine auto-injector, assuring the correct dosage _____

Demonstrates safe handling of epinephrine auto-injector _____

Demonstrates the correct procedure for giving epinephrine by auto-injector _____

Describes how to access emergency medical services, school nurse, student's parents (or other persons), student's physician _____

Comments:

Signatures: Supervised by _____ RN

Staff Person _____

Date: _____

Social-emotional Well-being of Students with Life-Threatening Food Allergies

- Examination of the emotional and psychosocial welfare of students with life-threatening food allergies as it relates to and is influenced by such students' membership in the school community and how such students are included or excluded from participating in school events.

- Examination of how instances of isolation or targeting of students with life-threatening food allergies by other students, school staff or school policy are addressed by the school or district administration.

I. Background

The most common issue school-aged children face is feeling different from their peers and the concept of wanting to be normal (Diana et al., 2003). Because food is such an integral part of social norms, whether in the cafeteria or in a classroom celebration, the unique accommodations that students may require can influence feelings about self, or may even lead to the targeting of the student. So, while the primary safety concern for a student with life-threatening food allergies is exposure to an allergen, a secondary concern is the exclusion or isolation of a student because of their condition. And while young children may unintentionally expose themselves to an allergen, exposure can also be due to bullying, as when a classmate exploits the child's weakness by threatening him or her with an allergen. There has been a surge in the prevalence of bullying due to food allergies with an increase of 18% in children from 1997-2007 (Ravid et al., 2012). Bullying is a serious issue in cases of food allergies because a bully cannot only cause psychological damage, but can also use the allergen as a weapon to cause physical harm. In serious cases, this type of bullying can be fatal. Bullying can include waving the allergen in the child's face or touching the child with the allergen (Lieberman et al., 2010). Thus, the "inherent imbalance of power," as Lieberman et al. (2010) coin it, sets children with food allergies at a disadvantage from the start. This is not the typical form of bullying that focuses on a child's appearance, personality traits, or hobbies, yet it can have similar effects: feelings of embarrassment, humiliation, sadness and even depression (Lieberman et al., 2010). Children with food allergies, much like children with diabetes, must learn to manage and accept responsibility of their food allergies, and bullying adds unnecessary stress to this lifestyle. Parents share the child's struggle when meticulously planning the child's diet and responding to skeptical parents or family and friends without food allergies. It is therefore a constant concern for

parents who expect schools to protect their children, especially from bullying (Mullarky et al., 2016). The negative feedback a child with food allergy receives from non-food allergy families can induce negative feelings and shame. Both the stress of maintaining an allergen-free diet and protecting the child from harm can create overprotective and hypersensitive parenting, which shelters a child from the realities of his or her condition (Valentine & Knibb, 2011). Children with food allergies often struggle to adjust to different social environments and situations properly due to both “over-responding and under-responding” patterns of families who struggle to achieve a positive balance.

A number of studies have been completed looking at the psychological impact on children and adolescents with food allergies. Lyons et al. (2004) found that food allergies in adolescents was associated with increased anxiety levels and Avery et al. (2003) reported that peanut allergic children expressed more anxieties about eating and had higher levels of anxiety and fear associated with managing their allergy than children with diabetes. Perhaps, food allergic children are aware of the immediate risk associated with accidental ingestion of allergen, whereas diabetic children are less aware of long-term implications of their condition. In contrast, King et al. (2009) found that children with peanut allergy rated separation anxiety as significantly higher than their siblings and girls with peanut allergy had greater anxiety over physical injury than boys with peanut allergy. Patten and Williams (2007) investigated the association between food allergy and anxiety and depression in a large cohort of people aged 15 and over using diagnostic interviews. Those with self-reported professionally diagnosed food allergy reported significantly higher rates of major depression, bipolar disorder, panic disorder and social phobia than those with no food allergy.

II. Current Regulations, Guidelines and Policies

A. Federal Law

Several Federal laws or programs potentially affect the social and emotional well-being of students with life-threatening food allergies.

Students with life-threatening food allergies may qualify for Section 504 plans, for students with disabilities, under the federal Rehabilitation Act of 1973. A 504 plan may include a variety of accommodations to address social-emotional well-being.

Several federally assisted meal programs, including the National School Lunch Program and School Breakfast Program, operate in public and nonprofit private schools and residential child care institutions. The U.S. Department of Agriculture (USDA) provides funding for these low-cost or free meals to children and implements the nutritional standards based on the Healthy, Hunger Free Kids Act. Any meals prepared in schools receiving Federal funding for school meals, must adhere to USDA standards. In such schools, accommodations for special dietary needs must also fulfill the USDA standards.

The USDA published guidelines, *Accommodating Children with Special Dietary Needs*, in 1995, and minor revisions were made in 2001. Since that time, significant changes have occurred in relevant laws affecting this document, and as of October 7, 2016, the USDA's published guidelines were being revised to incorporate more current versions of Americans with Disabilities Act, Section 504 of the Rehabilitation Act of 1973, and the Individuals with Disabilities Education Act (IDEA).

B. Connecticut State Law

District Plans: As of August 15, 2012, each local and regional board of education was required by Connecticut General Statute § 10-212c to implement a plan based on the Guidelines for the Management of Students with Life-Threatening Food Allergies and Glycogen Storage Disease. Additionally, each district was required to make the plan available to parents on a website and by annual notification. It should be noted that as of 2016, school districts were required by statute to notify parents of 37 different policies on an annual basis. Additionally, Connecticut Association of Boards of Education recommends that districts notify parents of 53 other important policies. While each policy is important enough to garner the attention of CABE or legislation to single out its contents, the number of policies now required to be highlighted, leaves some question about how much of the 90 policies are truly being underscored.

The CSDE Guidelines were updated in 2012, two years prior to the CDC issuing guidelines for the management of life-threatening food allergies in schools. The CSDE guidelines contain minimal information about addressing the social-emotional well-being of students with food allergies and glycogen storage disease.

CGS § 12-212c indicates that the State Guidelines will include “a process for the development of individualized health care and food allergy action plans for every student with a life-threatening food allergy, and a process for the development of individualized health care and glycogen storage disease action plans for every student with glycogen storage disease.” The Individualized Health Care Plan (IHCP) may or may not address the social well-being of the student.

Bullying: CGS § 10-222d. defines “bullying” in specific terms: “Bullying shall include, but not be limited to, a written, oral or electronic communication or physical act or gesture based on any actual or perceived differentiating characteristic, such as race, color, religion, ancestry, national origin, gender, sexual orientation, gender identity or expression, socioeconomic status, academic status, physical appearance, or mental, physical, developmental or sensory disability, or by association with an individual or group who has or is perceived to have one or more of such characteristics.”

It should be noted that the definition does not specifically include “special dietary requirements,” but the definition is not limited to the terms listed.

Safe School Climate: CGS § 10-222d. defines “School climate” to mean “the quality and character of school life with a particular focus on the quality of the relationships within the school community between and among students and adults.”

CGS § 10-222d requires “each local and regional board of education shall develop and implement a safe school climate plan to address the existence of bullying and teen dating violence in its schools.”

Since September 1, 2014, each local and regional board of education has been required to have an CSDE-approved safe school climate plan in place and available on the district and school internet sites and student handbooks.

Each school in the district is required to complete an assessment, biennially, using the school climate assessment instruments, including surveys, approved and disseminated by the Department of Education. School climate assessments must be submitted to the department.

In turn, the Department of Education must submit a report annually to the Legislature.

The Department of Education, in consultation with the State Education Resource Center, the Governor’s Prevention Partnership, the Commission on Children and the Connecticut Coalition Against Domestic Violence must establish a state-wide safe school climate resource network which makes available to all schools information, training opportunities and resource materials to improve the school climate to diminish bullying and teen dating violence.

The Department of Education must provide, within available appropriations, annual training to school employees on safe school climate. Such training may be presented in person by mentors, offered in statewide workshops or through on-line courses.

Beginning July 1, 2012, and each school year thereafter, the superintendent of each local or regional board of education was required to appoint, from among existing school district staff, a district safe school climate coordinator. The district safe school climate coordinator is responsible for implementing the district’s safe school climate plan and collaborating with the safe school climate specialists, the board of education for the district and the superintendent of schools of the school district on a number of topics. The topics include the prevention, identification and response to bullying in the schools of the district. Additionally the safe school climate coordinator is charged with providing data and information, in collaboration with the superintendent of schools of the district, to the Department of Education regarding bullying, and meeting with the safe school climate specialists at least twice during the school year to discuss issues relating to bullying in the school district and to make recommendations concerning amendments to the district’s safe school climate plan.

For the school year commencing July 1, 2012, and each school year thereafter, the principal of each school, or the principal’s designee, shall serve as the safe school climate specialist and shall (1) investigate or supervise the investigation of reported acts of bullying in the school in

accordance with the district's safe school climate plan, (2) collect and maintain records of reports and investigations of bullying in the school, and (3) act as the primary school official responsible for preventing, identifying and responding to reports of bullying in the school.

For the school year commencing July 1, 2012, and each school year thereafter, the principal of each school shall establish a committee or designate at least one existing committee in the school to be responsible for developing and fostering a safe school climate and addressing issues relating to bullying in the school. Such committee shall include at least one parent or guardian of a student enrolled in the school appointed by the school principal.

Any such committee shall: (A) Receive copies of completed reports following investigations of bullying, (B) identify and address patterns of bullying among students in the school, (C) implement the provisions of the school security and safety plan, developed pursuant to CGS § 10-222m, regarding the collection, evaluation and reporting of information relating to instances of disturbing or threatening behavior that may not meet the definition of bullying, (D) review and amend school policies relating to bullying, (E) review and make recommendations to the district safe school climate coordinator regarding the district's safe school climate plan based on issues and experiences specific to the school, (F) educate students, school employees and parents and guardians of students on issues relating to bullying, (G) collaborate with the district safe school climate coordinator in the collection of data regarding bullying, in accordance with the provisions of subsection (b) of CGS § 10-222d and subsection (a) of s CGS § 10-222h, and (H) perform any other duties as determined by the school principal that are related to the prevention, identification and response to school bullying for the school.

C. Connecticut State Department of Education

As mentioned in the previous section, CSDE is required by statute to address positive school climate through support, monitoring and reporting. Additionally, the CSDE influences issues connected with the social-emotional development of all students, whether they have life-threatening food allergies or not, through its work with nutrition and school wellness programs and curriculum.

Nutrition and School Wellness

The Richard B. Russell National School Lunch Act, as amended by the Healthy Hunger-Free Kids Act of 2010 (HHFKA), requires a unified accountability system designed to ensure that participating school food authorities (SFAs) comply with National School Lunch Program (NSLP) and School Breakfast Program (SBP) requirements. The Act also requires an accountability system that conducts Administrative Reviews to evaluate Program requirements for NSLP and SBP during a three-year cycle. The CSDE oversees the Administrative Reviews in Connecticut. Each local educational agency that participates in the National School Lunch Program or other federal Child Nutrition programs is required by federal law to establish a local school wellness policy for all schools under its jurisdiction. The monitoring of local school wellness policies falls under the General Areas of the Administrative Review. The scope of this monitoring may

require the State Department of Education to assess how areas of the local educational agency, other than the school food service, implement their local school wellness policy responsibilities, as applicable. Approximately 85% of districts in Connecticut participate in the NSLP and/or SBP.

Food services that provide NSLP and/or SBP for students with special dietary requirements must ensure that meals meet both USDA nutritional requirements as well as the accommodation. A review of the lunch menu in a couple of districts showed that while alternative choices were available to students with food allergies, students were often limited to one other choice, and sometimes, this was a salad.

Curriculum

The CSDE also recently developed the Social, Emotional and Intellectual Habits Framework to address social and emotional learning.

“The Kindergarten through Grade Three Social, Emotional and Intellectual Habits Framework builds from the foundational skills in the Cognitive and Social and Emotional Development Domains of the CT Early Learning and Development Standards, highlighting the continued growth and development that must be supported over the early elementary years.”

It addresses development of a positive self-concept, development of a positive attitude toward learning, identification and understanding of emotions of self and others, and development of positive interpersonal relationships. The curriculum does not specifically address the social and emotional well-being of students with food allergies.

D. Federal Guidelines

The Centers for Disease Control and Prevention published Voluntary Guidelines for Managing Food Allergies In Schools and Early Care and Education Programs in 2014. The guidelines include several sections that address positive school climate and the emotional impact of food allergies on students and their parents.

According to the CDC Guidelines

“Schools and ECE programs should foster a climate that promotes positive psychological and social development; that actively promotes safety, respect, and acceptance of differences; and fosters positive interpersonal relationships between staff members and children and between the children themselves. The psychosocial climate is influenced by clear and consistent disciplinary policies, meaningful opportunities for participation, and supportive behaviors by staff members and parents.

“Children with food allergies need an environment where they feel secure and can interact with caring people they trust. Bullying, teasing, and harassment can lead to psychological distress for children with food allergies, which could lead to a more severe

reaction when the allergen is present. A positive psychosocial climate—coupled with food allergy education and awareness for all children, families, and staff members—can help remove feelings of anxiety and alienation among children with food allergies.

“To create a positive psychosocial climate, staff members, children, and parents must all work together. School nurses, school counselors, or mental health consultants can provide leadership and guidance to set best practices and strategies for a positive psychosocial climate. Staff members should promote and reinforce expectations for a positive and supportive climate by making sure the needs of children with food allergies are addressed. For example, they can avoid using language and activities that isolate children with food allergies and encourage everyone’s help in keeping the classroom safe from food allergens. Children can help develop classroom rules, rewards, and activities.

“All children and staff members share responsibility for preventing bullying and social isolation of children with food allergies. School and ECE program staff should recognize that acceptance by peers is one of the most important influences on a child’s emotional and social development. Among adolescents, food allergy education and awareness can be an effective strategy to improve social interactions, reduce peer pressure, and decrease risk-taking behaviors that expose them to food allergens. Children should be expected to treat others with respect and to be good citizens, not passive bystanders, when they are aware of bullying or peers who seem troubled. Children should understand the positive or negative consequences associated with their actions. Rules and policies against bullying behavior should be developed in partnership with staff members, families, and children. They should be posted in buildings; published in school handbooks; and discussed with staff members, children, and families. All children and staff members should be encouraged to report bullying and harassment of any child with food allergies.”

E. State Guidelines

At least sixteen states publish guidelines that address the management of life-threatening food allergies in the school setting. Not all states’ guidelines address the social-emotional well-being of students. However, many do. Connecticut’s guidelines, which were published in 2012, two years prior to the publication of the CDC Guidelines, do not specifically address psychosocial well-being of students, but indicate that school district-management plans “should strike a balance between the education, health, social normalcy and safety needs of the individual student with life-threatening food allergies and glycogen storage disease and the education, health and safety needs of all students.”

The following recommended practices from Connecticut’s Guidelines, while not specifically identified as being for the social-emotional benefit of students, may help to address social-emotional well-being of students with life-threatening food allergies:

- providing options, but not requiring, for allergen-free zones such as the classroom, lunch tables or cafeteria zone to decrease exposure to allergen;
- providing options for food-free common areas (such as libraries, music and art rooms);
- enforcing relevant school policies, such as those that prohibit eating on the school buses;
- planning for school celebrations (such as, birthdays, school parties and holiday events) which should include alternatives to food for celebrations;
- considering individual student and family privacy needs and preferences in determining appropriate plans, as not all students or families will need or want to use an allergen-free zone during the school day.

F. District Policies and Practices

Connecticut Association of Boards of Education, Inc. (CABE) provides sample policies and regulations for Connecticut school districts to adopt and revise as needed. One such policy “packet” addresses the “Accommodation of Students with Special Dietary Needs: Food Allergy Management.” There are four versions of the policy and two versions of accompanying regulations from which districts can choose. Most policies focus on the safety of students and reflect the CSDE Guidelines without addressing practices to address the social-emotional well-being of students.

IV. Gap Analysis

A gap analysis of the Connecticut Guidelines and the CDC Guidelines indicates that the Connecticut Guidelines are lacking many of the good practices which address social-emotional well-being and that are outlined in the CDC Guidelines (Attachment D). The Connecticut Guidelines should be updated to address psychosocial issues. Including a chart such as the one in Attachment E could foster understanding about the differences in accommodations and inclusive practices.

One concern raised during the course of the Task Force is that of food in classrooms and how students with food allergies are included or isolated when food is part of celebrations or curriculum. According to the survey of public schools superintendents, most districts (78%) notify the parents of food-allergic students prior to classroom activities that involve food. Thirty-seven percent of districts have food-free classrooms. Eighty percent of districts modify curriculum that includes food (e.g., science, cultural, cooking or nutrition classes) to allow students with food allergies to fully participate.

Public comments submitted to the Task Force suggest that while many districts and schools institute policies and practices that promote inclusion of students with food allergies, there are many instances when the practical aspects of inclusion run up against school traditions, issues

of safety, and a lack of familiarity with food allergies. Additionally, practices, even within a district can be inconsistent.

Some schools have chosen to ban nuts from the district (e.g., Derby), not only to address safety, but also, in part, to address the social exclusion of students. However, this practice in Derby is being reevaluated due to practicable issues. A district-wide ban also begs the question of whether other life-threatening food allergies should be addressed in a similar manner, potentially leading to multiple foods - dairy, fish, egg, wheat, soy, etc. – being banned. Given the already challenging task to the food service provider of preparing appetizing meals, addressing the USDA standards, and meeting the needs of students with IHCPs, these school-wide bans could be difficult to implement. There is no reasonable or fail-safe way to prevent an allergen from inadvertently entering into a building, and even with such a ban in place, a school or program still has a responsibility to properly plan for children with any life-threatening food allergies.

Many schools grapple with the balance between upholding safety and social integration in the cafeterias and in the classroom when allergens are present. How to maintain separate tables or areas for students with life-threatening allergies while maintaining inclusive practices can prove challenging but not impossible. Additionally, questions about how to accommodate and include students with life-threatening allergies in after-school programs, whether the events are PTA-sponsored movies or sports competitions, must be addressed. Training staff in allergy policies and procedures as well as how to use an epi-pen is low/no budget and can foster inclusion.

Over the last several years, safe school climate legislation has resulted in a focused effort to develop systems and plans in every district to proactively address the social-emotional well-being of all students. Additionally, a K-5 Social, Emotional and Intellectual Habits Framework for curriculum has recently been adopted by the State Department of Education. Despite these initiatives, specific practices addressing the social well-being of students with life-threatening food allergies remain variable. Additionally, many of the public comments that the Task Force received indicated that there is a sense of “backlash” against parents who advocate for required accommodations. The Task Force was made aware of many situations where students were unnecessarily and, sometimes, unwittingly isolated. As examples:

- Students with food allergies are often seated in the cafeteria at a separate table (38% of districts according to the superintendents’ survey). Given that many school cafeterias now serve nut-free meals, students with nut allergies could sit at tables designated for purchased and/or nut-free meals. Some schools have addressed the issue of isolation of allergic students by requiring students with nut-containing meals to sit at a separate table.
- Many parents/guardians of students with life-threatening food allergies feel that they must choose between the safety of their child riding a school bus with limited access to emergency services and their child’s need to be part of a social experience.

Social-emotional Well-being of Students

- Many students with life-threatening food allergies do not feel safe participating in after school activities. Organizations are required to provide accommodations for students with disabilities, particularly if the district provides free or reduced-cost facilities, publically announces or disseminates flyers about an event or program to the student body or parents, or allows the organization to identify itself with the school and use the school logo (*Unified Sch. District 19 IDELR 883 (OCR Apr 28, 1993)*) yet, only 42% of districts have an adult who is trained to recognize anaphylaxis and administer epinephrine available for after school activities (according to the superintendents' survey).

The Task Force recognizes that there are a wide variety of districts throughout Connecticut, with as many varied communities. It should not be left up to each parent to advocate for services in isolation and without the oversight of a body that can ensure consistency from one district to another. On the other hand, given individual needs of students and the differences in communities throughout Connecticut, a balance must be struck between too much prescriptive direction to districts and too little. Several states - Washington, New Jersey, South Carolina - have education ombudspersons to help promote equity in education. Although difficult to quantify, there is value to avoiding unnecessary conflicts and having a neutral body to offer a broad perspective to both districts and parents about what is fair and reasonable, thus avoiding unnecessary litigation. An ombudsperson, designated as a CSDE staff member, could serve as a liaison to assist districts, parents and community members in helping to resolve problems, complaints, conflicts, and other school-related issues when normal procedures have failed. An ombudsperson or CSDE liaison could:

- Serve as a resource to complainants by providing an alternative to the formal complaint process.
- Assist complainants in clarifying the process regarding their issues and generating options for resolution.
- Serve as a resource to districts by providing the tools for effective problem resolution.
- Make recommendations to Superintendent.
- Hear anonymous requests for information and provide referrals.
- Conduct informal interventions and mediation.

Attachment D

Gap Analysis between CDC guidelines and CSDE guidelines

CDC	CSDE
Includes a section on the emotional impact on children with food allergy and their parents in the introduction.	Not included
Includes a section on creating and maintaining a healthy and safe educational environment and talks about creating a positive psychological climate under priorities for managing food allergies.	Not included
Includes section on literature and data on bullying and isolation of children with food allergy.	Not included
Under roles and responsibilities:	
<p>1) School District</p> <ul style="list-style-type: none"> • Create and maintain a healthy and safe educational environment. • Create a positive psychosocial climate. • Provide food allergy education to increase awareness for all children, families and staff members to help remove feelings of anxiety and alienation among children with food allergies. • Staff members should promote and reinforce expectations for a positive and supportive climate by making sure the needs of children with food allergies are addressed • Rules and policies against bullying behavior should be developed in partnership with staff members, families and children and posted in buildings, published in school handbooks and discussed with staff members, students and families. • All children and staff members should be encouraged to report bullying and harassment of any child, including 	Not included

<p>those with food allergies.</p> <ul style="list-style-type: none"> • Develop and consistently enforce policies that prohibit discrimination and bullying against all students, including those with food allergies. • Ensure that children are not subject to discrimination on the basis of their disability. • Student with disabilities must be educated with typical children to the maximum extent possible in the least restrictive environment. • Treat the student with food allergies the same as other students. • Make recommendations for safety and inclusion in the classroom, cafeteria, transportation, school events, PE and Recess. • Consider designated allergy-friendly seating arrangement in the classrooms • Consider designated allergy-friendly seating during meals, which is open to any child eating foods free of identified allergens. 	<p>School options may include establishing allergen free zones, such as a child’s individual classroom, allergen free lunch table(s) or areas in the cafeteria and food – free zones, such as libraries and music rooms, as well as enforcing relevant school policies, such as those that prohibit eating on the school buses. Individual student and family privacy needs and preferences should be considered in determining appropriate plans. Not all students or families will need or want to use and allergen-free zone during the school day.</p>
<p>2) School Nurse</p> <ul style="list-style-type: none"> • Work with school counselors and other school staff to provide emotional support to students with food allergies. • Work with other school staff and parents to create a safe environment for students with food allergies. • Promote an environment that encourages students with food allergies to tell a staff member if they are bullied because of their allergy. 	<p>School Nurse Not included</p>

Social-emotional Well-being of Students

<p>3) Classroom Teacher</p> <ul style="list-style-type: none"> • Create ways for students with food allergies to participate in all class activities. • Promote a positive psychological climate by encouraging supportive and positive interactions between students; reinforcing the school’s rules against discrimination and bullying; taking action to address all reports of bullying or harassment of a student with a food allergy. • Tell parents if their child has been bullied, and report all cases of bullying to the school administrator. • Tell parents and the school nurse if you see negative changes in a student’s academic performance or behavior. 	<p>Classroom Teacher</p> <ul style="list-style-type: none"> • Educate classmates to avoid endangering, isolating, stigmatizing or harassing students with food allergies. Be aware of how the student with food allergies is being treated; use this opportunity to teach community caring; and enforce school rules/policies about bullying and threats.
<p>4) School Counselors and Other Mental Health Services Staff (includes psychologists and social workers)</p> <ul style="list-style-type: none"> • Encourage staff to support a broad range of school-based mental health promotion efforts to support all students that promote positive interactions between students, build a positive school climate, encourage diversity and acceptance, discourage bullying, and promote student independence. • Reinforce the school’s rules against bullying and discrimination. • Take action to address all reports of bullying or harassment of a student with a food allergy. • Tell parents if their child has been bullied, report all cases of bullying to school administrators. 	<p>School Psychologist</p> <ul style="list-style-type: none"> • Educate classmates to avoid endangering, isolating, stigmatizing or harassing students with food allergies. Be aware of how the student with food allergies is being treated; use this opportunity to teach community caring; and enforce school rules/policies about bullying and threats.
<p>5) School Food Service Managers and Staff</p> <ul style="list-style-type: none"> • Promote a positive psychosocial climate in the cafeteria through the following actions: encourage 	<p>Food Service Personnel</p> <ul style="list-style-type: none"> • Create specific areas that will be allergen safe as needed.

Social-emotional Well-being of Students

<p>supportive and positive interactions between students; reinforce the school rules against bullying and discrimination; take action to address all reports of bullying or harassment of a student with a food allergy; report all cases of bullying and harassment against students, including those with food allergies, to the school administrator, school nurse, or school counselor.</p>	
<p>6) Students Not included</p>	<p>Students</p> <ul style="list-style-type: none"> Report any instances of teasing or bullying to an adult immediately.
<p>7) Medical Director</p>	<p>Medical Director</p>
<ul style="list-style-type: none"> Work with school staff and parents to create a safe environment for students with food allergies Work with school counselors, the school nurse, and other school staff to provide emotional support to students with food allergies. Promote an environment that encourages students with food allergies to tell a staff member if they are bullied or harassed because of their allergy. 	<p>Not Included</p>
<p>8) Coaches</p>	<p>Coaches</p>
<p>Not included</p>	<ul style="list-style-type: none"> Conduct sports and after school activities in accordance with all school policies and procedures regarding life-threatening allergies.
<p>9) Bus Drivers and Transportation Staff</p>	<p>School Bus Company</p>
<ul style="list-style-type: none"> Encourage supportive and positive interactions between students Reinforce the school's rules against discrimination and bullying. Report all cases of bullying or harassment of students, including those with food allergies, to the school administrator 	<p>Not included</p>
<p>10) School Administrator</p>	<p>School Administrator</p>
<ul style="list-style-type: none"> Make sure that students with food 	<p>Not included</p>

Social-emotional Well-being of Students

<p>allergies have an equal opportunity to participate in all school activities and events.</p> <ul style="list-style-type: none">• Reinforce the school's rules that prohibit discrimination and bullying as they relate to students with food allergies.	
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Attachment E

Exclusion vs. Inclusion Accommodation Chart

Exclusion	Accommodation	Inclusion
Parents provide all special treats and are present at activities they deem problematic (resulting in lost time from work/extra expense); student sent out in the hall or to the library when there's unsafe food in the classroom	Provided with "safe" area and own food ("treat box")	No foods used in the classroom that are not safe for student, including holiday parties, math teaching aids, language/culture days, etc.; special classroom party fund is collected and used to purchase all treats; trained school staff member is available for field trips or other high-risk activities
Eats lunch in own area, separate from other children	Eats at an allergen-free table	Allergic child eats wherever he/she wants; children who bring peanut-containing foods sit at a specific peanut table
Cannot participate in after-school activities involving food (pancake breakfasts, sports events with concessions, ice cream socials, etc.)	School ensures there is at least one allergen-free option for the child at each event	School social events are food-free
Burden of educating staff members about allergies falls to parent and/or no education occurs	School passively disseminates information/allergy "sheet" on a limited basis, such as a classroom binder or only to the health staff	School actively trains all individuals throughout the district, including transportation staff and school volunteers
Brings lunch from home; no accommodation for forgotten lunch; school food service takes no responsibility for allergic reactions	School food service periodically provides ingredient lists to students who request it	Food service trained in cross-contamination; documented procedure with multiple check-points for allergic student lunch; identified substitute lunch available that is allergen-free

References:

Avery NJ, King RM, Knight S, Hourihane JO. (2003). Assessment of quality of life in children with peanut allergy. *Pediatric Allergy Immunology*, 14, 378–382.

Centers for Disease Control and Prevention. (2013) *Voluntary Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs*. Washington, DC: US Department of Health and Human Services, 21, 39, 57-76.

Guthrie, DW, Bartsocas C, Jarosz-Chabot P, Konstantinova M. (2003). Psychosocial Issues for Children and Adolescents with Diabetes: Overview and Recommendations. *Diabetes Spectrum*, 16(1), 7-12.

King RM, Knibb RC, Hourihane JO. (2009). Impact of peanut allergy on quality of life, stress and anxiety in the family. *Allergy*, 64 (10), 461–468.

Lieberman J, Weiss C, Furlong TJ, Sicherer SH. (2010). Bullying among pediatric patients with food allergy. *Journal of Allergy Clinical Immunol.*, 105, 267-271.

Lyons AC, Forde EM. (2004). Food allergy in young adults: perceptions and psychological effects. *J Health Psychology*, 9, 497–504.

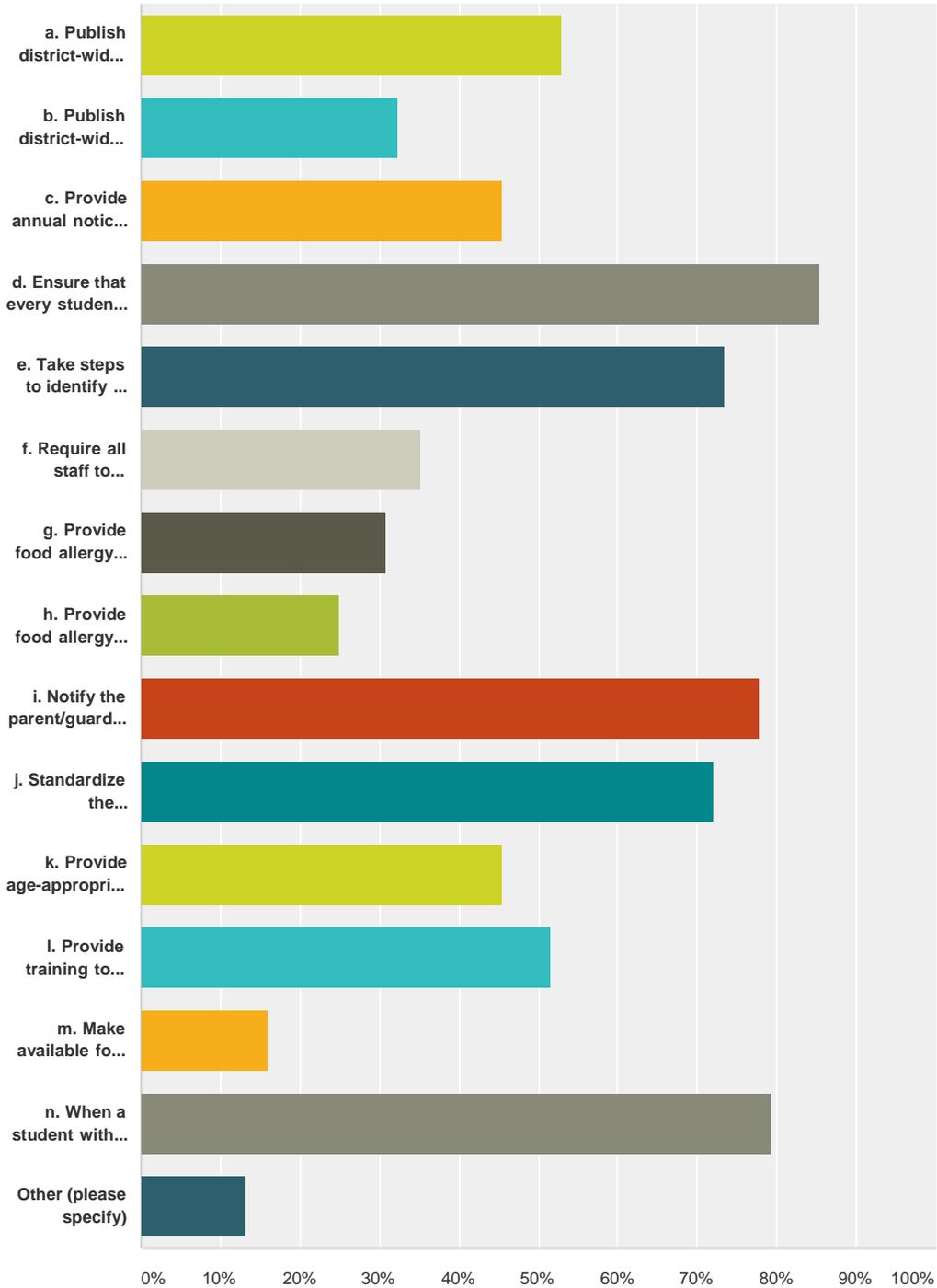
Mullarkey C. (2016). Food allergy and bullying: the implications for parents and children with food allergies. *Applied Psychology OPUS*.

Patten SB and Williams JV. (2007). Self-reported allergies and their relationship to several Axis I disorders in a community sample. *Int J Psychiatry Med.*, 37(1), 11-22.

Valentine AZ and Knibb RC. (2011). Exploring quality of life in families of children living with and without a severe food allergy. *Appetite (Print)*, 57(2), 467-474.

Q1 What specific strategies/protocols do you use to protect students with food allergies in your district? Please indicate all that apply:

Answered: 68 Skipped: 0



Answer Choices	Responses
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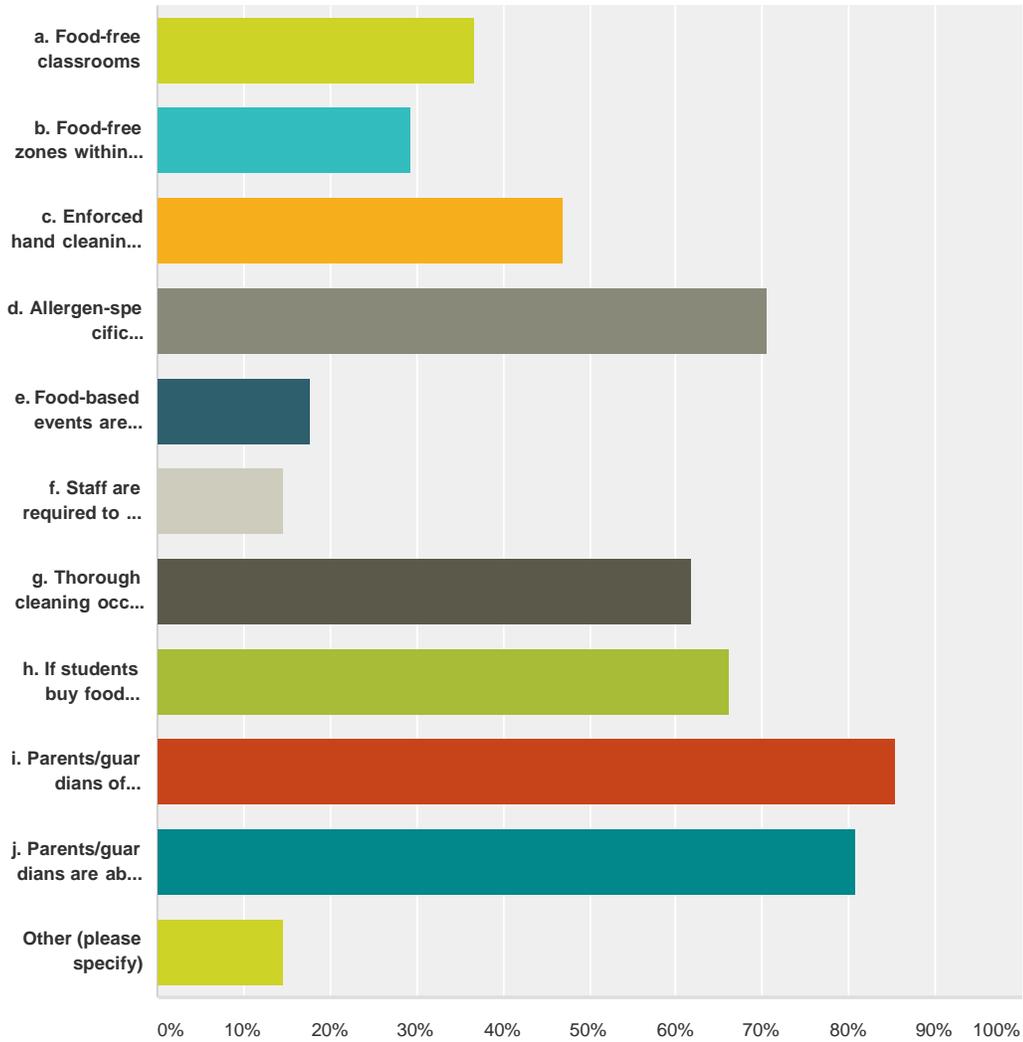
a. Publish district-wide food allergy plan on public website	52.94%	36
b. Publish district-wide food allergy plan on internal website	32.35%	22
c. Provide annual notice of the district-wide food allergy plan to parents and guardians	45.59%	31
d. Ensure that every student with known food allergies has an Emergency Care Plan signed by a health care provider	85.29%	58
e. Take steps to identify and locate students with life-threatening food allergies and publicize procedural rights under Section 504	73.53%	50
f. Require all staff to complete in-person or online food allergy training	35.29%	24
g. Provide food allergy education as part of curriculum to all students	30.88%	21
h. Provide food allergy education/resources to entire parent/guardian community (parents of students with and without food allergies)	25.00%	17
i. Notify the parent/guardian of food allergic students prior to any curricular activity or celebration so the parent/guardian can provide safe food for their student	77.94%	53
j. Standardize the communication about students with food allergies (their IHCP and/or 504 plans) to appropriate staff, including substitutes	72.06%	49
k. Provide age-appropriate education about food-allergy bullying/shaming/harassment	45.59%	31
l. Provide training to staff on food allergy bullying/shaming/harassment	51.47%	35
m. Make available food allergy plans in Spanish and/or languages other than English	16.18%	11
n. When a student with food allergies is in a class in which food is a part of the curriculum (e.g. science experiments, cultural studies, cooking and nutrition class), curriculum is modified to allow students with food allergies to fully participate	79.41%	54
Other (please specify)	13.24%	9
Total Respondents: 68		

#	Other (please specify)	Date
1	Food service staff trained on identification of food allergy reactions, cpr and first aid	12/7/2016 12:55 PM
2	No outside food permitted for celebrations. Teachers are discouraged from using food for curriculum activities. If they do so, a permission slip goes home to any food allergic child detailing the food used and purpose. Parent must approve of the food being used for their child's participation or an alternative must be provided	12/6/2016 10:39 AM
3	All students with severe food allergies have IHCP and EMP as well as Bus EMP. Not 504s unless additional accommodations are needed above and beyond the IHCP.	11/30/2016 10:16 AM
4	All parents of students with life-threatening allergies are given a copy of the district plan with everyone responsibilities. We try get them to come in to discuss in person and go over the entire plan. We reach out to parents and offer them training in EpiPen administration if they are not comfortable.	11/23/2016 10:59 AM
5	Both staff and students receive annual education on bullying/safe climate. Parents of children K - 8 with allergy receive annual letter with link to policy.	11/22/2016 11:22 AM
6	signs on doors for students with allergies, safe setting in cafe	11/21/2016 11:02 PM
7	allergen free classrooms	11/21/2016 3:22 PM

8	In addition to the above, at least one volunteer staff member is trained to recognize the signs and symptoms of a anaphylaxis, and the appropriate first aid to treat it. All of our schools have standing orders to administer Epinephrine as a life-saving measure, even if not previously identified as being highly allergic to a substance.	11/21/2016 2:32 PM
9	Our district no longer uses for in curriculum and/or for celebrations/projects/rewards	11/21/2016 1:23 PM

Q2 Which of the following practices are implemented in your district? Please indicate all that apply:

Answered: 68 Skipped: 0



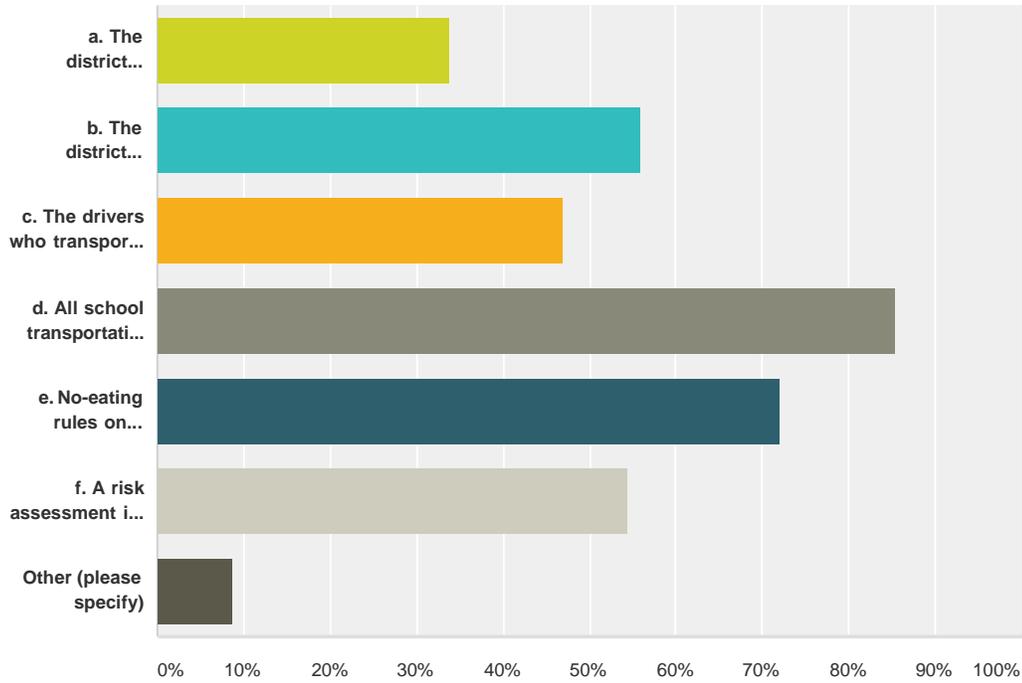
Answer Choices	Responses
a. Food-free classrooms	36.76% 25
b. Food-free zones within classrooms	29.41% 20
c. Enforced hand cleaning by all students after all eating	47.06% 32
d. Allergen-specific restrictions in classrooms	70.59% 48
e. Food-based events are restricted to cafeteria or outdoors	17.65% 12

f. Staff are required to eat only in staff lounge and/or cafeteria	14.71%	10
g. Thorough cleaning occurs any time food has been in a classroom, whether it is before/after school or during school hours	61.76%	42
h. If students buy food prepared or sold in the school, they are permitted to sit at the tables designated for allergen-free students regardless of whether they, themselves, have life-threatening food allergies.	66.18%	45
i. Parents/guardians of students with life-threatening food allergies are able to opt their students out of sitting at separate lunch tables	85.29%	58
j. Parents/guardians are able to opt-out of food sharing activities for their students	80.88%	55
Other (please specify)	14.71%	10
Total Respondents: 68		

#	Other (please specify)	Date
1	No outside food is permitted for classroom and/or school celebrations. The only outside food permitted is the individual student's snack from home. There is no food sharing permitted. Stock epinephrine is available in all schools for the administration for a first time allergic reaction in school.	12/6/2016 10:39 AM
2	Parents of allergy students asked to bring in approved treats in case of a surprise unlabeled shared snack brought in.	11/30/2016 10:16 AM
3	parents/gurardians encouraged to provide safe snacks to be kept at school for student to have during a classroom celebration or activity where foods are served that they have not approved	11/29/2016 12:45 PM
4	We look at each case individually and develop a plan to meet the student specific need. All cafeteria tables are washed after each lunch wave.	11/23/2016 10:59 AM
5	Specific peanut free classrooms	11/22/2016 8:14 PM
6	Elementary aged children eat snack in their classroom. Handwashing is enforced in specific elementary classrooms on case by case basis.	11/22/2016 11:22 AM
7	Stock Epi pens in each school for undiagnosed allergy students. Per CT regulations each school has team that has been trained to give Epi-pen if school nurse is not available. This team receives yearly training on Emergency Care, signs and symptoms of allergic reactions and how to use the Epi pen.	11/22/2016 10:53 AM
8	Wellness Policy and plan in place that addresses food allergies and food practices in schools	11/22/2016 8:17 AM
9	no celebrations with food, no food as rewards, and we have food safe classrooms and zones.	11/21/2016 2:14 PM
10	see (other) above	11/21/2016 1:23 PM

Q3 What specific strategies or protocols do you institute for transportation? Please indicate all that apply:

Answered: 68 Skipped: 0



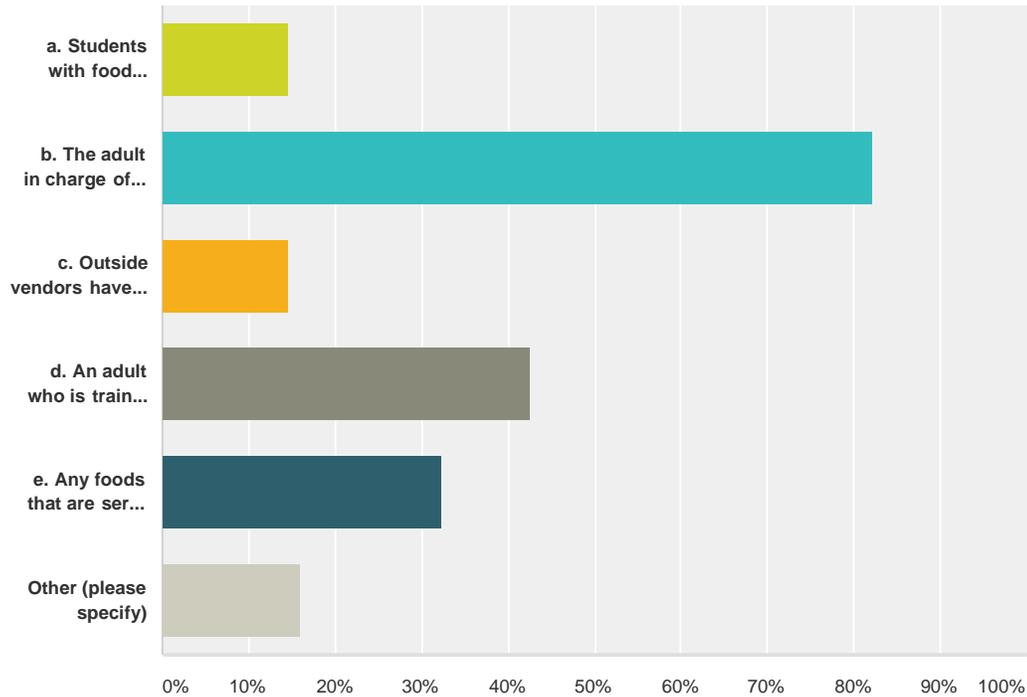
Answer Choices	Responses
a. The district requires all drivers who transport children to/from school (including field trips, sports and other school activities) to have training in the signs and symptoms of anaphylaxis and the administration of epinephrine	33.82% 23
b. The district ensures that drivers who transport children know the identity of the students who have food allergies and which students carry epinephrine	55.88% 38
c. The drivers who transport children follow a written plan or protocol for the handling of food allergic emergencies	47.06% 32
d. All school transportation vehicles have communication devices (e.g. radios) in addition to cell phones.	85.29% 58
e. No-eating rules on transportation are enforced, including transportation for field trips, sports and after school activities.	72.06% 49
f. A risk assessment is performed as part of field trip planning	54.41% 37
Other (please specify)	8.82% 6
Total Respondents: 68	

#	Other (please specify)	Date
1	unsure	12/6/2016 1:36 PM

2	The bus company is contracted by the district and therefore must follow their company's protocol for emergencies, which is to pull over and call 911. The company does not permit the training of epinephrine administration.	12/6/2016 10:39 AM
3	It is impossible to train all bus drivers since they can change at a moments notice. We have a contract with our bus company the procedure is that if a student has a medical issue on the bus the driver calls the dispatcher, 911 is called and the driver is informed of any medical issue the student may have.	11/23/2016 10:59 AM
4	Transportation policy is no eating on bus. Difficult to enforce.	11/22/2016 11:22 AM
5	Bus Company has their own protocols	11/21/2016 2:13 PM
6	I don't know	11/21/2016 1:11 PM

Q4 How do you ensure that food-allergic students are able to safely participate in all before and after school activities (including PTA/PTO, clubs, sports, etc.)? Please indicate all that apply:

Answered: 68 Skipped: 0



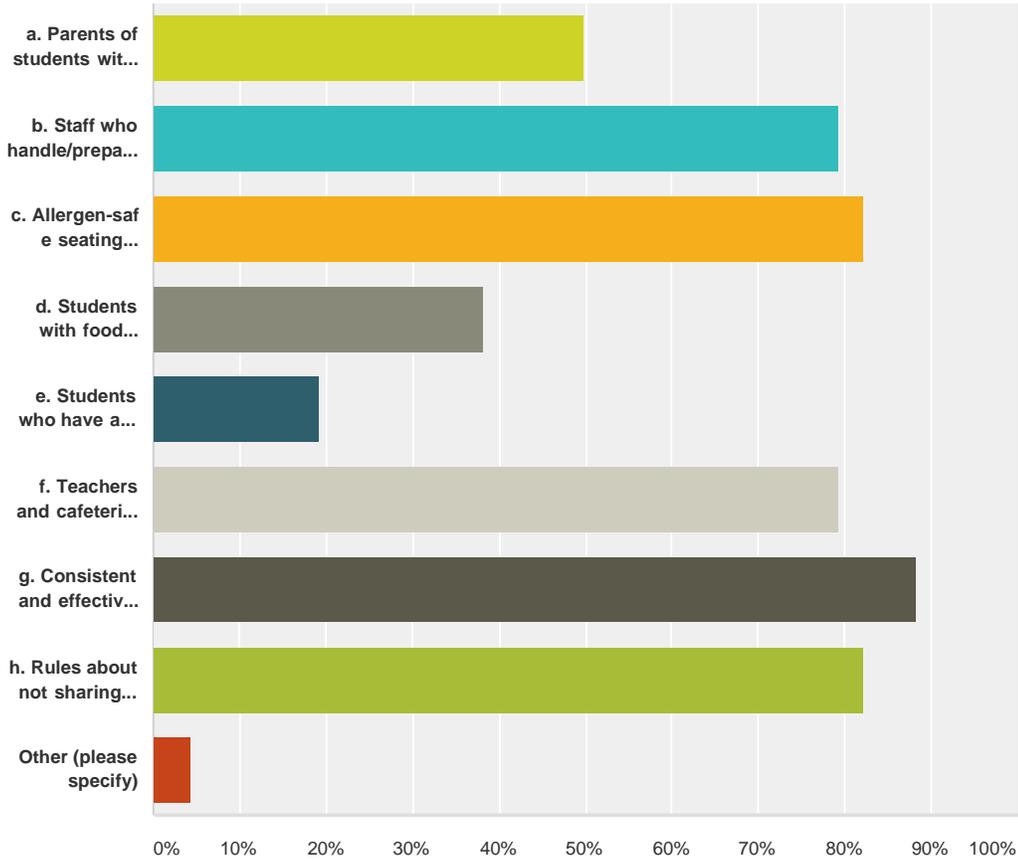
Answer Choices	Responses
a. Students with food allergies are directed to the programs in which exposure would be limited or nonexistent	14.71% 10
b. The adult in charge of the program is notified of any students with IHCP and/or 504 plans	82.35% 56
c. Outside vendors have communication system in place in case of allergic reaction/emergency	14.71% 10
d. An adult who is trained to recognize anaphylaxis and administer epinephrine is available at all times	42.65% 29
e. Any foods that are served are safe for all students to consume	32.35% 22
Other (please specify)	16.18% 11
Total Respondents: 68	

#	Other (please specify)	Date
1	Meal and snack accommodations provided to students in after school and summer programs	12/7/2016 12:55 PM
2	Coach training for sports	12/6/2016 12:26 PM
3	Ongoing communication with small community	12/6/2016 11:00 AM
4	Adults are trained to administer epinephrine for known food allergic students.	12/6/2016 10:39 AM
5	no food is served at these activities	12/6/2016 10:28 AM

6	Any programs outside the school hours are the responsibility of the program and parents.	11/30/2016 10:16 AM
7	For sports the coaches are giving the information so there is someone available at all time. Parents are informed that there is no nurse available at after school programs. We would provide a nurse if the student had a 504 that required the needs of a nurse for any student.	11/23/2016 10:59 AM
8	Coaches and teachers taking students on field trips are required to consult with the nursing department regarding student medical alerts. For clubs and PTA sponsored activities parents are responsible for informing the adult in charge. There is an adult trained in emergency EpiPen administration during the school day.	11/22/2016 11:22 AM
9	safe alternatives are available	11/21/2016 11:02 PM
10	Item D is in effect, but only during regular school hours as mandated by law.	11/21/2016 2:32 PM
11	all coaches are informed of LTA and are medication delegated.	11/21/2016 2:14 PM

**Q5 Which of the following procedures are used to ensure that students with food allergies are safe when eating in school, whether it is breakfast, lunch, or snack?
Please indicate all that apply:**

Answered: 68 Skipped: 0



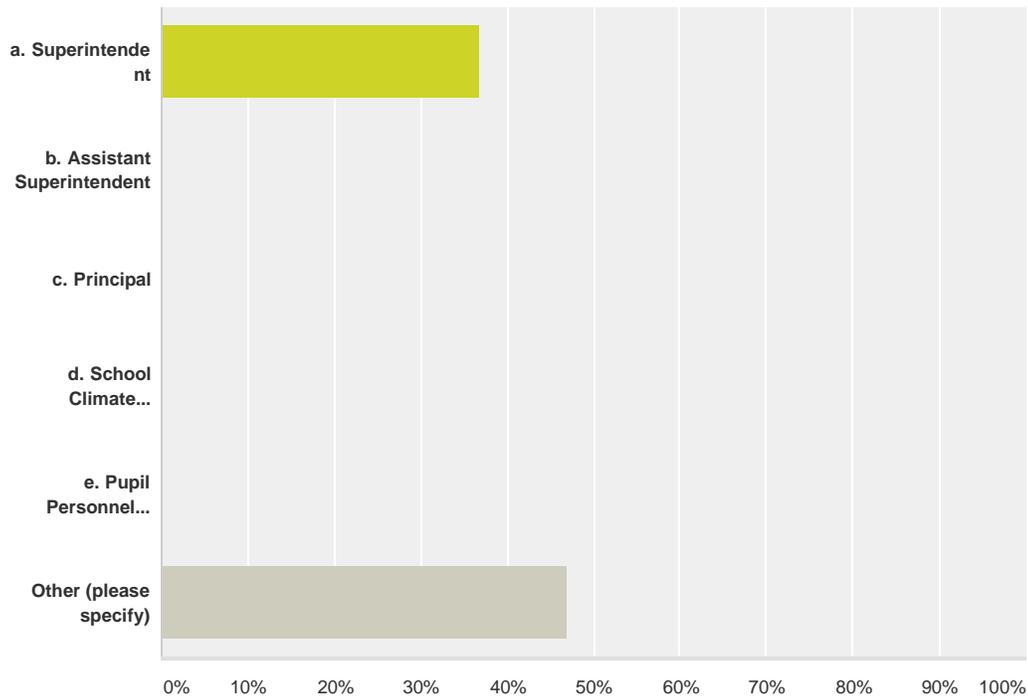
Answer Choices	Responses
a. Parents of students with food allergies are asked to submit physician-signed USDA Special Dietary Needs form	50.00% 34
b. Staff who handle/prepare/provide food are trained to identify potential allergens in food labels and are able to contact food vendors/manufacturers if needed	79.41% 54
c. Allergen-safe seating options are provided in the cafeteria or classroom in collaboration with school staff and parents	82.35% 56
d. Students with food allergies are required to sit at designated tables in cafeteria or classroom	38.24% 26
e. Students who have a lunch that contains allergens are required to sit at designated tables in the cafeteria or classroom	19.12% 13
f. Teachers and cafeteria staff are trained to recognize anaphylaxis	79.41% 54

g. Consistent and effective cleaning/sanitation methods are employed	88.24% 60
h. Rules about not sharing food between students are maintained	82.35% 56
Other (please specify)	4.41% 3
Total Respondents: 68	

#	Other (please specify)	Date
1	Designated table are determined based on age level and student awareness of allergen. Protocols implemented at the elementary level may not exist at the high school level.	12/6/2016 10:39 AM
2	These answers are grade specific	11/28/2016 4:49 AM
3	Parents can opt to have student sit at allergen free table. Any student with an allergen free lunch can sit at this table.	11/22/2016 11:22 AM

Q6 What is the position of the person filling out this survey:

Answered: 68 Skipped: 0



Answer Choices	Responses
a. Superintendent	36.76% 25
b. Assistant Superintendent	5.88% 4
c. Principal	2.94% 2
d. School Climate Coordinator	0.00% 0
e. Pupil Personnel Director	7.35% 5
Other (please specify)	47.06% 32
Total	68

#	Other (please specify)	Date
1	Supervisor of Health and Physical Education	12/7/2016 12:55 PM
2	school nurse	12/7/2016 11:44 AM
3	Food Service Director	12/7/2016 11:18 AM
4	Food Service Director	12/6/2016 1:36 PM
5	Nursing Supervisor	12/6/2016 12:26 PM
6	Food Service Director	12/6/2016 11:09 AM
7	Nurse supervisor	12/6/2016 11:09 AM
8	Health Services Coordinator	12/6/2016 10:39 AM

9	Health Services Coordinator	12/6/2016 10:25 AM
10	Assistant to the Superintendent	12/6/2016 10:04 AM
11	Nurse	12/6/2016 9:50 AM
12	school nurse	12/5/2016 11:05 AM
13	District Nurse Coordinator	12/1/2016 4:02 PM
14	School Nurse	11/30/2016 10:16 AM
15	School Nurse Supervisor	11/29/2016 12:45 PM
16	Finance Director	11/29/2016 9:05 AM
17	School Health Supervisors (with School Nurse input)	11/28/2016 12:57 PM
18	School Nurse	11/23/2016 12:14 PM
19	School Nurse Coordinator	11/23/2016 10:59 AM
20	District Nursing Supervisor	11/22/2016 11:22 AM
21	School Nurse/School Nurse Coordinator	11/22/2016 10:53 AM
22	School Health Supervisor	11/22/2016 9:04 AM
23	District nursing supervisor	11/22/2016 8:37 AM
24	Special Services Director	11/22/2016 8:36 AM
25	School Nurse Coordinator	11/21/2016 4:05 PM
26	Charge Nurse	11/21/2016 2:32 PM
27	Health Care Coordinator	11/21/2016 2:14 PM
28	Director of Dining Services	11/21/2016 2:06 PM
29	School Nurse Consultant	11/21/2016 1:41 PM
30	Director of Nutrition Services	11/21/2016 1:25 PM
31	School Nurse	11/21/2016 1:23 PM
32	coordinator	11/21/2016 1:11 PM

Q7 Approximately how many students are in your district?

Answered: 68 Skipped: 0

#	Responses	Date
1	19,000	12/7/2016 12:55 PM
2	don't know this information	12/7/2016 11:44 AM
3	3300	12/7/2016 11:18 AM
4	6000	12/6/2016 1:36 PM
5	525	12/6/2016 1:14 PM
6	6648	12/6/2016 12:26 PM
7	1100	12/6/2016 11:16 AM
8	2400	12/6/2016 11:09 AM
9	8000	12/6/2016 11:09 AM
10	1750	12/6/2016 11:04 AM
11	105	12/6/2016 11:00 AM
12	430	12/6/2016 11:00 AM
13	11,000	12/6/2016 10:39 AM
14	13,000	12/6/2016 10:34 AM
15	8500	12/6/2016 10:28 AM
16	1100	12/6/2016 10:28 AM
17	3,400	12/6/2016 10:25 AM
18	1280	12/6/2016 10:19 AM
19	1900	12/6/2016 10:16 AM
20	360	12/6/2016 10:04 AM
21	7000	12/6/2016 9:52 AM
22	867	12/6/2016 9:52 AM
23	102	12/6/2016 9:50 AM
24	101	12/6/2016 9:50 AM
25	1257	12/5/2016 11:05 AM
26	860	12/1/2016 4:02 PM
27	253	11/30/2016 10:16 AM
28	10,000	11/29/2016 4:48 PM
29	1900	11/29/2016 12:45 PM
30	11000	11/29/2016 9:05 AM
31	1000	11/28/2016 1:34 PM
32	6,000 counting private schools (one K-8, two High Schools)	11/28/2016 12:57 PM
33	1400	11/28/2016 4:49 AM
34	850	11/23/2016 12:27 PM

35	235	11/23/2016 12:14 PM
36	6030	11/23/2016 10:59 AM
37	2,900	11/23/2016 8:06 AM
38	4000	11/23/2016 5:25 AM
39	2650	11/22/2016 8:14 PM
40	700	11/22/2016 7:38 PM
41	443	11/22/2016 2:02 PM
42	4536	11/22/2016 11:22 AM
43	1717	11/22/2016 10:53 AM
44	850	11/22/2016 10:52 AM
45	3,700	11/22/2016 10:19 AM
46	18000	11/22/2016 9:04 AM
47	4100	11/22/2016 8:37 AM
48	850	11/22/2016 8:36 AM
49	1500	11/22/2016 8:28 AM
50	2850	11/22/2016 8:17 AM
51	2400	11/21/2016 11:02 PM
52	1400	11/21/2016 8:50 PM
53	1200	11/21/2016 5:34 PM
54	Easton (882), Redding (943), Region 9 (951)	11/21/2016 4:05 PM
55	2,300	11/21/2016 3:30 PM
56	3100	11/21/2016 3:22 PM
57	3218	11/21/2016 2:32 PM
58	350	11/21/2016 2:16 PM
59	1300	11/21/2016 2:14 PM
60	200	11/21/2016 2:13 PM
61	16,000	11/21/2016 2:06 PM
62	11,000	11/21/2016 1:41 PM
63	2300	11/21/2016 1:27 PM
64	2700	11/21/2016 1:25 PM
65	1985	11/21/2016 1:23 PM
66	9600	11/21/2016 1:17 PM
67	2500	11/21/2016 1:11 PM
68	6000	11/21/2016 1:01 PM

APPENDIX A

Q8 Which school district do you represent (optional)?

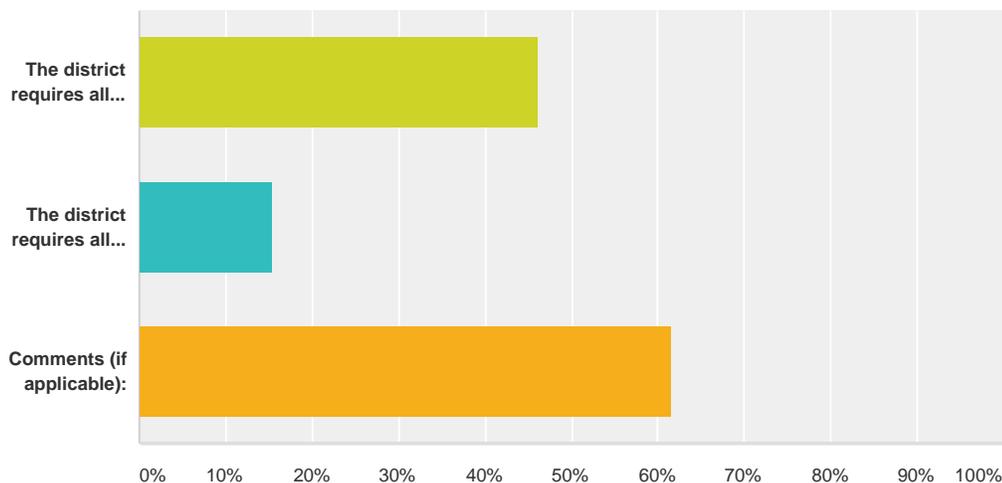
Answered: 34 Skipped: 34

#	Responses	Date
1	Waterbury Public Schools	12/7/2016 12:55 PM
2	Groton	12/7/2016 11:44 AM
3	Windham Public Schools	12/7/2016 11:18 AM
4	Southington	12/6/2016 12:26 PM
5	Wolcott Public Schools	12/6/2016 11:09 AM
6	Danbury	12/6/2016 10:39 AM
7	Bristol - Ellen Solek	12/6/2016 10:28 AM
8	Bethany Public School District	12/6/2016 10:04 AM
9	Stratford	12/6/2016 9:52 AM
10	Brooklyn Public Schools	12/6/2016 9:52 AM
11	Hampton	12/6/2016 9:50 AM
12	Windsor Locks	12/5/2016 11:05 AM
13	Barkhamsted	11/30/2016 10:16 AM
14	Fairfield	11/29/2016 4:48 PM
15	Coventry	11/29/2016 12:45 PM
16	danbury	11/29/2016 9:05 AM
17	Middletown	11/28/2016 12:57 PM
18	Bolton	11/23/2016 12:27 PM
19	Wallingford	11/23/2016 10:59 AM
20	Ellington	11/22/2016 8:14 PM
21	Region 12	11/22/2016 7:38 PM
22	Newtown	11/22/2016 11:22 AM
23	Stafford Public Schools	11/22/2016 10:53 AM
24	New Canaan	11/22/2016 8:37 AM
25	Regional School District # 8	11/22/2016 8:28 AM
26	Portland	11/21/2016 8:50 PM
27	Easton, Redding, and Region 9	11/21/2016 4:05 PM
28	Monroe	11/21/2016 3:22 PM
29	Preston	11/21/2016 2:16 PM
30	East Windsor Public Schools	11/21/2016 2:14 PM
31	Stamford	11/21/2016 2:06 PM
32	Cromwell	11/21/2016 1:23 PM
33	West Hartford	11/21/2016 1:17 PM
34	Glastonbury	11/21/2016 1:01 PM

APPENDIX A

Q1 What specific strategies or protocols do you institute for transportation? Please indicate all that apply:

Answered: 13 Skipped: 0



Answer Choices	Responses
The district requires all drivers who transport children to/from school (including field trips, sports and other school activities) to have training in the signs and symptoms of anaphylaxis.	46.15% 6
The district requires all drivers who transport children to/from school (including field trips, sports and other school activities) to have training in the the administration of epinephrine auto-injectors.	15.38% 2
Comments (if applicable):	61.54% 8
Total Respondents: 13	

#	Comments (if applicable):	Date
1	training provided to drivers with known allergies on the bus	12/19/2016 8:02 AM
2	Bus drivers are tined to call 9-1-1, the school and the bus company in the event of any medical emergency	12/15/2016 3:13 PM
3	NA	12/15/2016 9:36 AM
4	The bus drivers receive an emergency plan for allergy students but they are not trained in epipen administration. The nurse talks with the drivers.	12/15/2016 8:42 AM
5	Bus company will no allow drivers to be trained, students can carry their epipens on the bus if required.	12/14/2016 2:23 PM
6	Drivers are not trained but paras and teachers carry Epipens on field trips and or with assigned students on buses.	12/14/2016 12:28 PM
7	The extent of our district protocols with regard to transportation is that the drivers are notified who has special medical concerns, and they are instructed to call 911 for any ingestion/exposure to an allergen, or for any other serious situation.	12/14/2016 10:53 AM
8	All bus drivers have a Emergency Health Care plan (for each individual student) in the event of a allergic reaction-	12/14/2016 10:38 AM

APPENDIX A

Q2 If your district requires drivers to be trained to administer ephinephrine, who is responsible for conducting the training, and is there an associated cost? If this does not apply to your district please answer n/a.

Answered: 13 Skipped: 0

#	Responses	Date
1	NA	12/19/2016 8:02 AM
2	N/A - Not required in the State of Connecticut	12/15/2016 3:13 PM
3	The contracted bus company.	12/15/2016 11:30 AM
4	Bus drivers are not listed in the state regs as qualified personnel 10-212a 1 Am I missing something?	12/15/2016 9:36 AM
5	n/a	12/15/2016 8:42 AM
6	n/a	12/14/2016 2:23 PM
7	Drivers are not trained as per the bus company manager.	12/14/2016 12:28 PM
8	N/A	12/14/2016 12:04 PM
9	The school nurse. No additional cost.	12/14/2016 11:49 AM
10	Our Pd Committee sets up the training and the bus drivers watch the videos wit the rest of the staff every year opening day of PD.	12/14/2016 10:59 AM
11	N/A	12/14/2016 10:53 AM
12	n/a	12/14/2016 10:38 AM
13	Nursing Supervisoe	12/14/2016 9:36 AM

APPENDIX A

Q3 Title of Person responding to this question:

Answered: 13 Skipped: 0

#	Responses	Date
1	Superintendent	12/19/2016 8:02 AM
2	Supervisor of Health and Physical Education	12/15/2016 3:13 PM
3	BOE Executive Assistant	12/15/2016 11:30 AM
4	Superintendent	12/15/2016 9:36 AM
5	School nurse supervisor	12/15/2016 8:42 AM
6	Wendy Gage RN BSN NCSN	12/14/2016 2:23 PM
7	Heather Elken BSN, lead nurse	12/14/2016 12:28 PM
8	Superintendent of Schools	12/14/2016 12:04 PM
9	Principal	12/14/2016 11:49 AM
10	Superintendent	12/14/2016 10:59 AM
11	Charge Nurse	12/14/2016 10:53 AM
12	School Nurse Supervisor	12/14/2016 10:38 AM
13	Superintendent of Schools	12/14/2016 9:36 AM

APPENDIX A

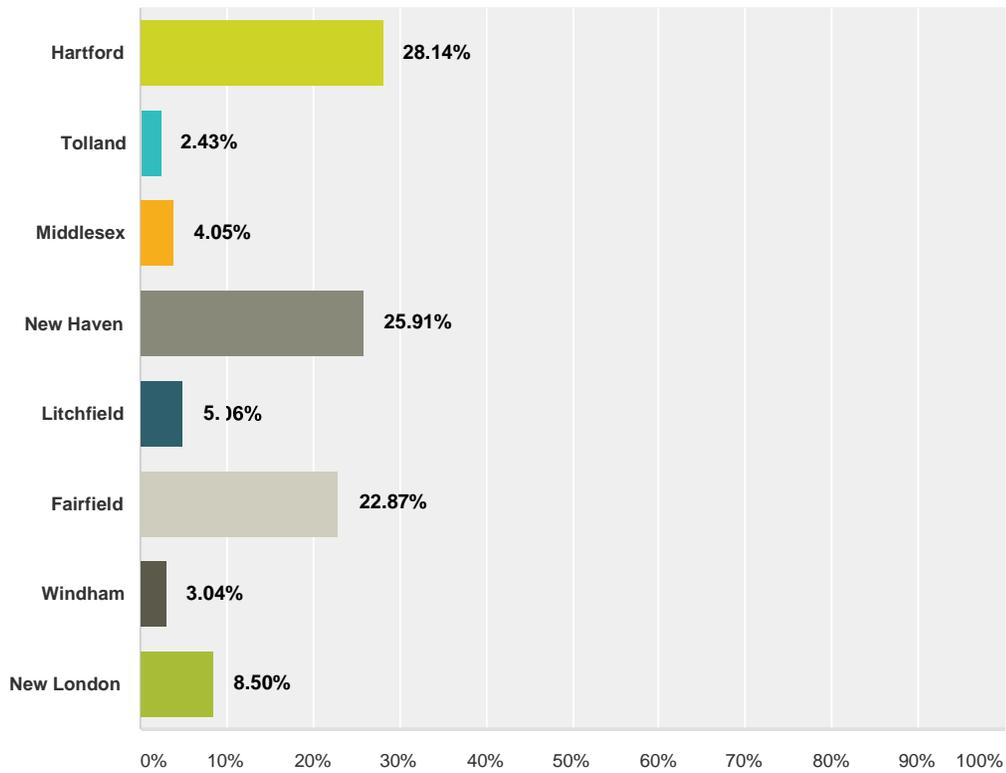
Q4 Which district do you represent?

Answered: 13 Skipped: 0

#	Responses	Date
1	Plainville	12/19/2016 8:02 AM
2	Waterbury	12/15/2016 3:13 PM
3	Bethany Public School District	12/15/2016 11:30 AM
4	Middletown	12/15/2016 9:36 AM
5	Woodbridge	12/15/2016 8:42 AM
6	East Windsor Public Schools	12/14/2016 2:23 PM
7	Oxford	12/14/2016 12:28 PM
8	East Lyme Public Schools	12/14/2016 12:04 PM
9	Preston	12/14/2016 11:49 AM
10	Canterbury	12/14/2016 10:59 AM
11	North Haven	12/14/2016 10:53 AM
12	Stafford Public Schools	12/14/2016 10:38 AM
13	Avon	12/14/2016 9:36 AM

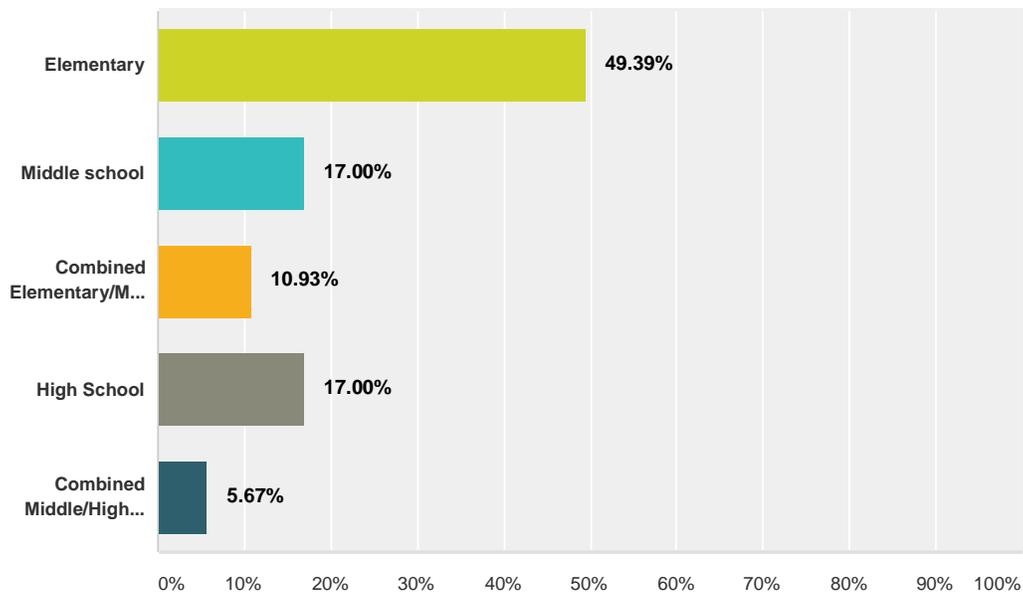
Q1 In what county is the school you work located?

Answered: 494 Skipped: 0



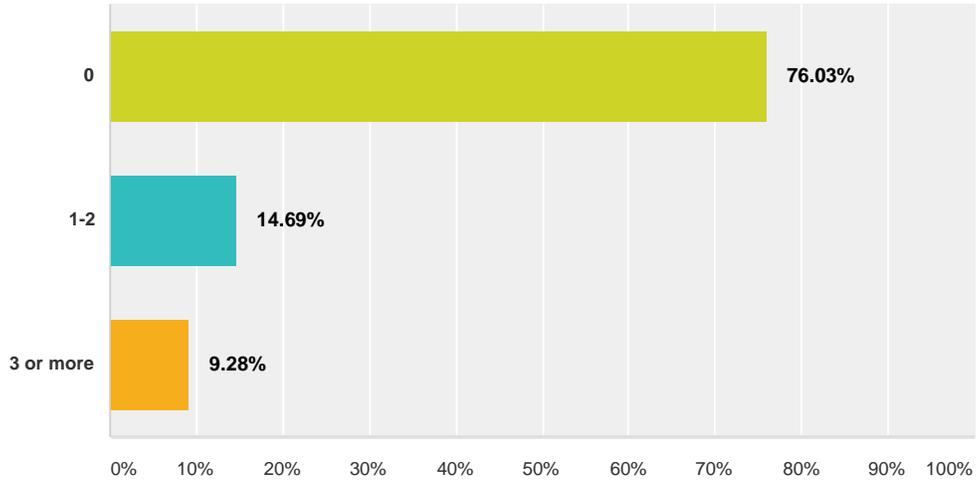
Q2 Which best describes the type of school where you work?

Answered: 494 Skipped: 0



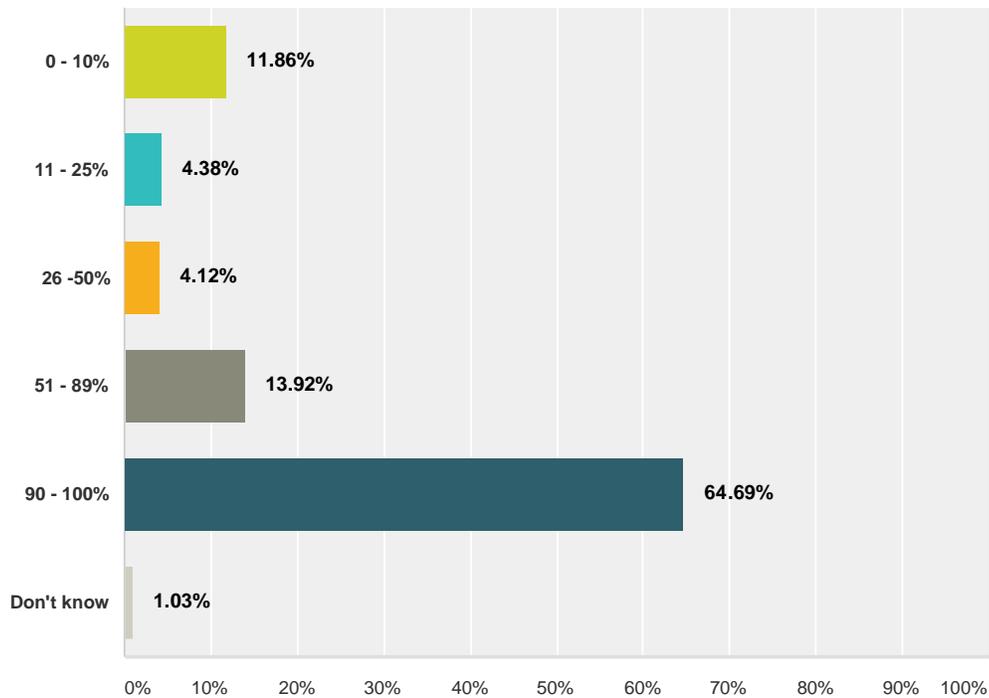
Q3 How many students required epinephrine administration in your school last school year (diagnosed or previously undiagnosed)?

Answered: 388 Skipped: 106

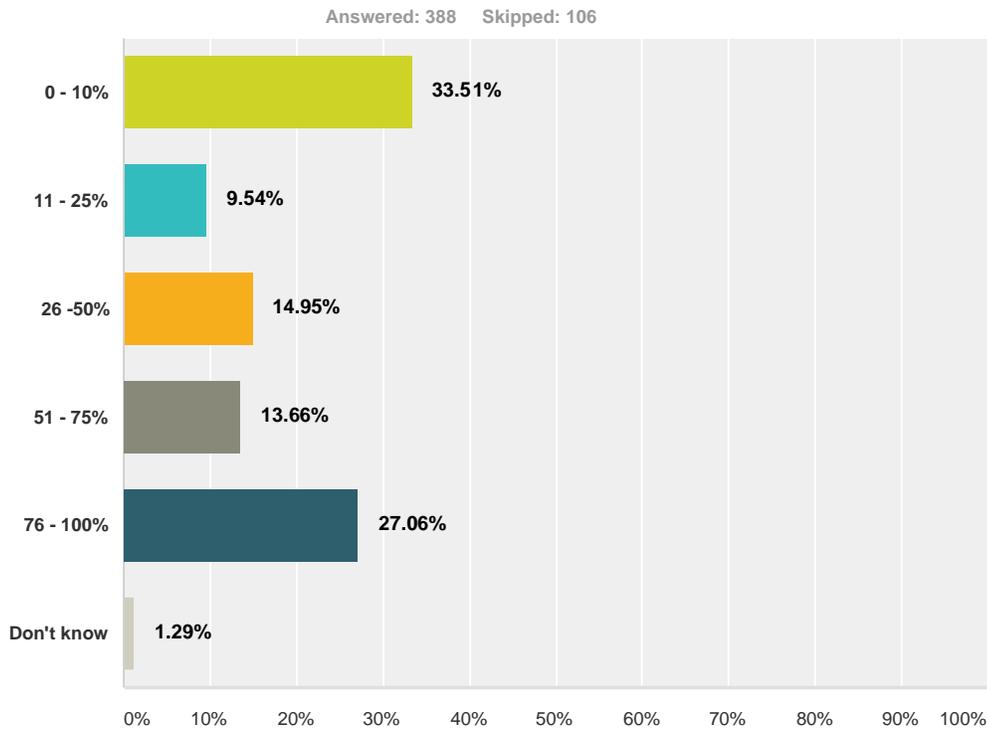


Q4 Please select the percentage range of students with a known life-threatening allergy who have their own supply of epinephrine in school (self-carry or in nurse office):

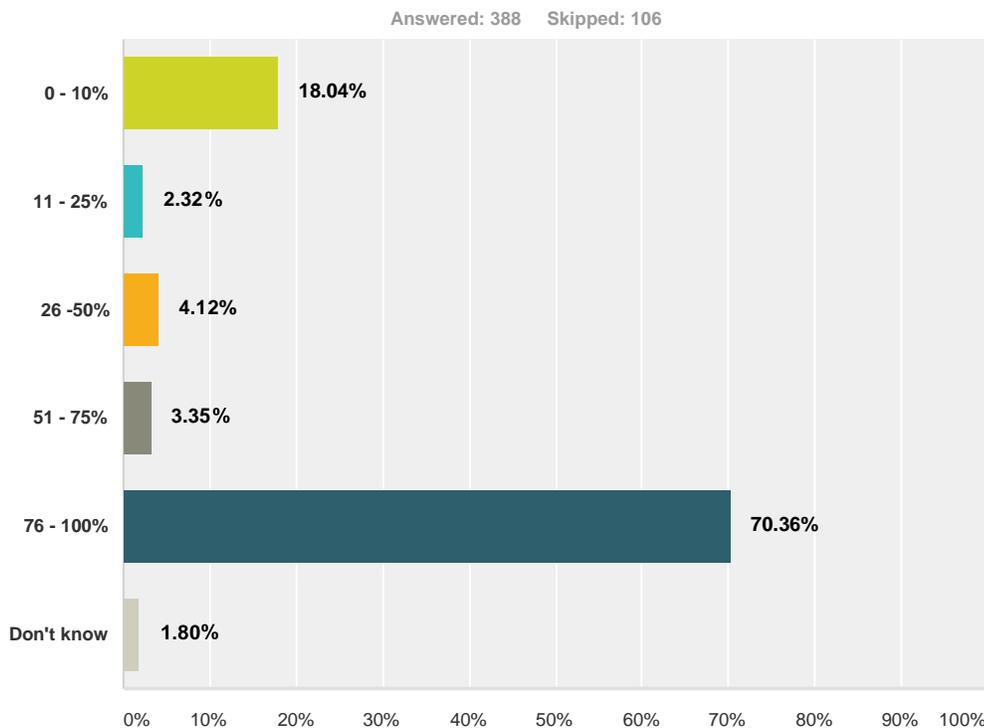
Answered: 388 Skipped: 106



Q5 Please select the percentage range of students whose emergency allergy plan has a medication authorization requiring the administration of Benadryl prior to administration of epinephrine:

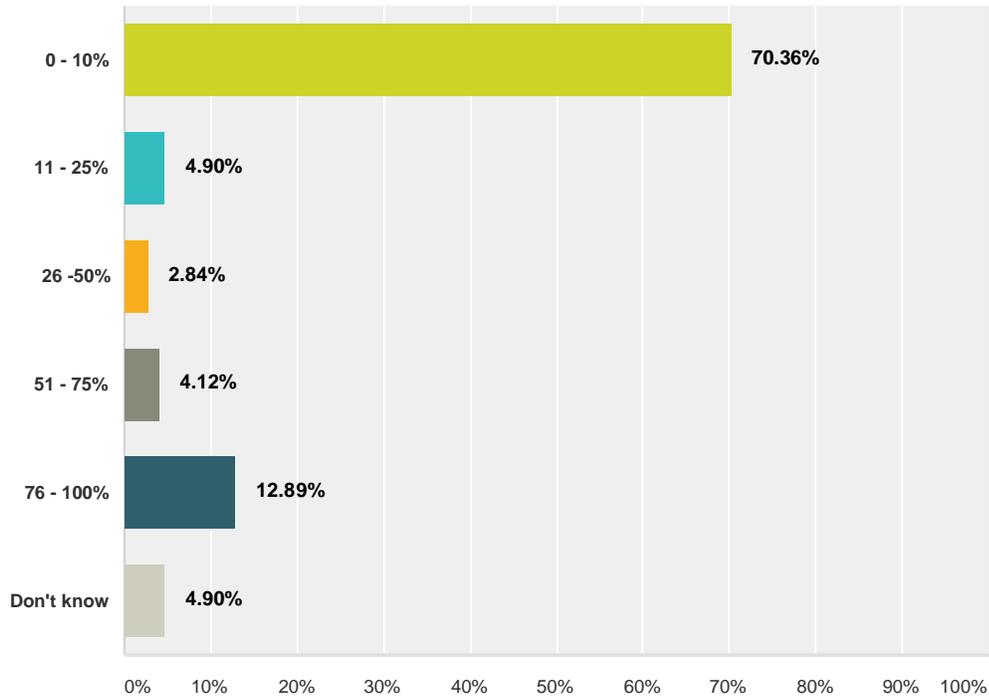


Q6 Please select the percentage range of students with a known life-threatening allergy who have an IHCP for their allergy:



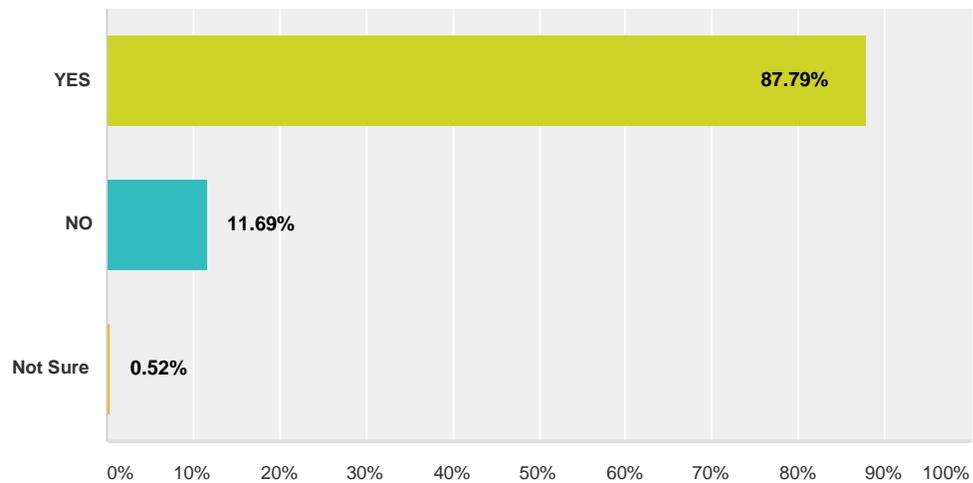
Q7 Please select the percentage range of students with a known life-threatening allergy who have 504 plan accommodations for their allergy:

Answered: 388 Skipped: 106



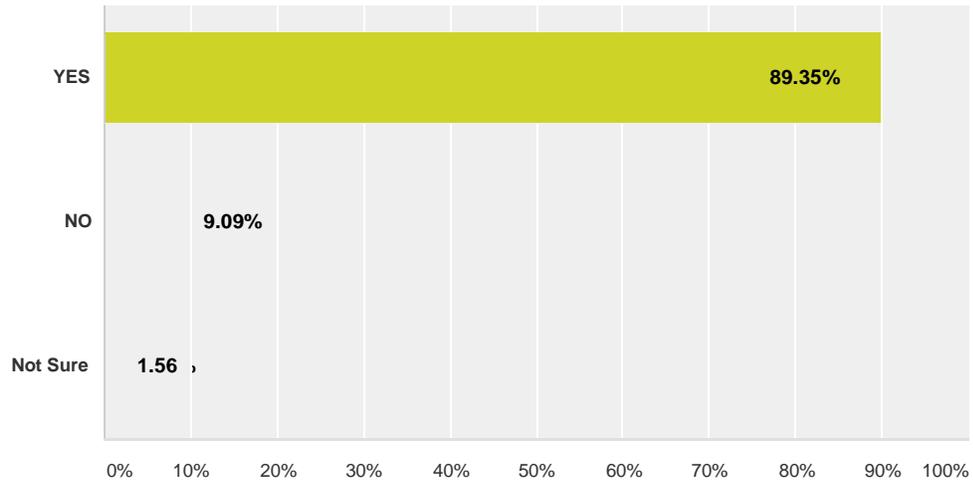
Q8 Do you have a stock epinephrine auto-injector accessible to staff who are trained to use it for any student who has anaphylaxis?

Answered: 385 Skipped: 109



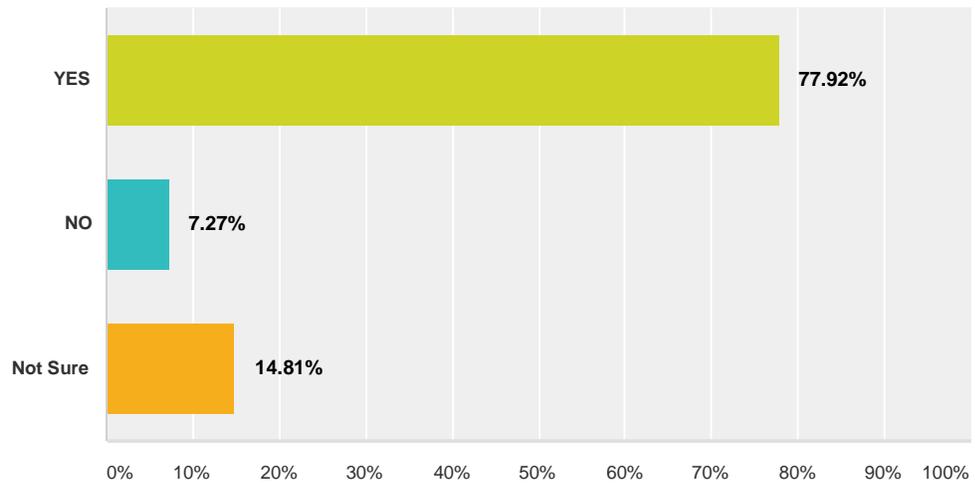
Q9 Do you have at least one non-nurse staff member trained to recognize anaphylaxis and administer epinephrine auto-injector for any student who has anaphylaxis?

Answered: 385 Skipped: 109



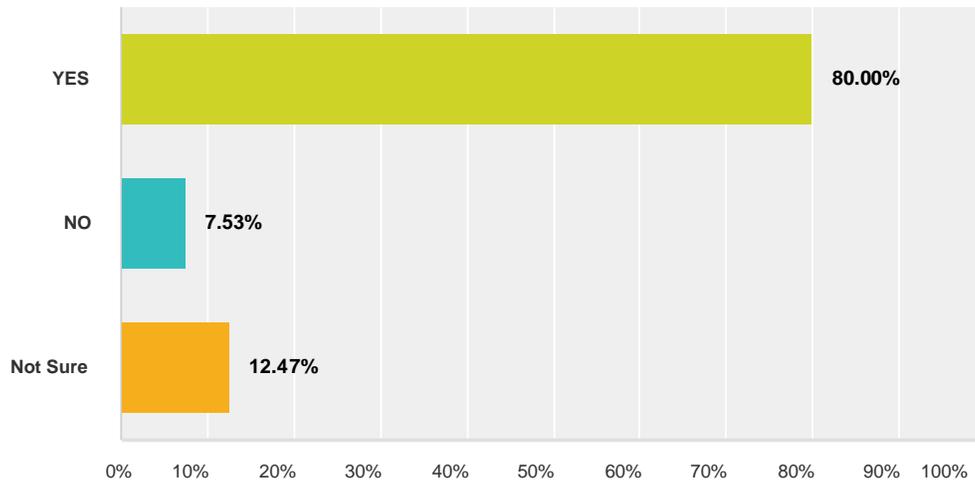
Q10 Do you think that the opt-out option for students to receive epinephrine auto-injector for anaphylaxis jeopardizes the safety of students?

Answered: 385 Skipped: 109



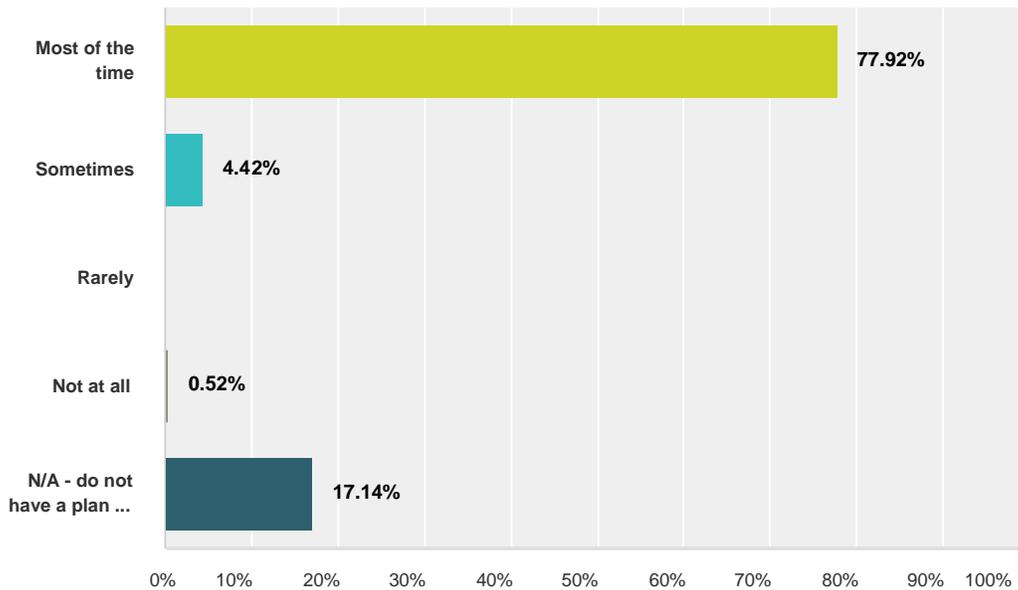
Q11 Do you have a district food allergy prevention and management plan?

Answered: 385 Skipped: 109



Q12 Does your school follow your district's food allergy prevention and management plan?

Answered: 385 Skipped: 109



Q17 Do you have any best practices that you'd like to highlight?

Answered: 163 Skipped: 311

#	Responses	Date
1	None at this time.	12/7/2016 12:47 PM
2	we do frequent teacher and support staff training and parent notification of our policies.	12/7/2016 11:47 AM
3	I try to do Emergency Care Plans with student's photo so that substitutes are aware of those with potential life threatening anaphylaxis	12/7/2016 11:45 AM
4	Not at this time	12/7/2016 11:34 AM
5	no birthday party celebrations that involve food. A notice is sent home by teacher that informs parent a food item will be served or part of a craft in the classroom.	12/7/2016 11:15 AM
6	We are a peanut/nut free PreK. Keeps it easier. In elementary school, non food treats for celebrations have rid us of the allergen problem.	12/7/2016 10:45 AM
7	On my medication doors, I have pictures of the students with severe allergies as well as what they are allergic to for quick reference for self or sub nurse. It is covered for privacy of course.	12/7/2016 9:48 AM
8	One of the policies that our school district follows is having all food brought into school for celebrations must be store bought and labeled and checked by the nurse. I feel that this helps to ensure the safety of all students in the classroom.	12/7/2016 8:53 AM
9	Our nurses communicate to Food Services with lists of children who are allergic to foods and when the student puts their lunch code into the touch pad, the computerized cash register lists food allergies so the cashier is a final surveyor of the tray to be sure food allergens are not on the tray.	12/6/2016 12:37 PM
10	Review at start of school year and update prior to field trips/outings	12/6/2016 12:05 PM
11	minimize celebrations, only packaged foods from safe snack list allowed, highlight fruits and vegetables for celebrations, increased communication between teachers and room mom's for food celebrations (only have 3 per year), responsibilities of parents, nurse and staff in school protocol.	12/6/2016 11:45 AM
12	Educating students and faculty on the proper use and administration of Epipens.	12/6/2016 11:28 AM
13	Every teacher has a list of their students with food allergies. They are asked to keep this in their sub-folder. Classrooms are kept nut free.	12/6/2016 10:36 AM
14	Make sure the school and adults that are with the students know what is going on and how to treat it. Review it with them often	12/6/2016 9:17 AM
15	none	12/6/2016 7:29 AM
16	ensuring that teachers receive the allergy alerts as soon as possible at the beginning of the school year and each time a new student begins school; making sure the teacher and student understand their roles in knowing/understanding the allergy.	12/5/2016 3:39 PM
17	We do have a nut free table in our lunchroom. There are strictly followed protocols which spill over to any community use of the room.	12/5/2016 2:26 PM
18	I always call home to remind parents/student to tell the teacher when they are going on a field trip where they will be keeping their epi-pen during the trip, and to notify the teacher as to where it is, in case she needed to adm it	12/5/2016 2:11 PM
19	We have a very specificsnack list that we are very strict about: if a person is to bring outside food into school to share (ie group snack in lower grades) it must come from the list or it is not allowed. We also changed to NON-food celebrations. Teachers are not supposed to celebrate with food or to reward with food. This takes some time for the teachers to get used to (like 6 months) but in the end it makes their job so much easier rather than having to police foods in the class.	12/5/2016 1:49 PM
20	We work very hard to make sure that all students with epipens have IHP's. We distribute the coupons from the epipen website to help parents buy epipens.	12/5/2016 1:38 PM
21	Last year we implemented a new policy where any celebration in school does not include food. This has greatly reduced the chance of an accidental ingestion of a unsafe food for the student with an allergy	12/5/2016 1:09 PM

22	assuring the cafeteria staff enter food allergies in the computer/cash register so when a student purchases food, worker can make sure no allergans are being purchased.	12/5/2016 12:23 PM
23	nut-safe tables and trash in the cafeteria, nut-safe classrooms for students with allergies	12/5/2016 12:17 PM
24	We train staff to give Epipen injections to each other rather than themselves to feel what it is like to give to another person. We ensure that staff member let student know that they are carrying their Epipen so they know who to look for in emergency.	12/5/2016 12:16 PM
25	Peanut/nut free table: only students who have nut allergy may sit there. Also, students who do NOT have lunch from home may sit there (and haven't bought PB&J for lunch). That way, unlabeled food brought from home is never an issue.	12/5/2016 11:54 AM
26	Going over signs and symptoms of Anaphylaxis with staff and practicing using an Epipen 3 times buring the school year at staff meetings	12/5/2016 11:33 AM
27	No just working with the faculty and students to avoid allergens	12/5/2016 11:14 AM
28	in our elementary schools, we have permission slips that go out to all the students when any food is being served in the classroom	12/5/2016 10:51 AM
29	Educating students about hand washing and avoiding foods that can potentially cause allergic reaction.	12/5/2016 10:45 AM
30	Washing hands after meals to prevent allergens reaching students.	12/5/2016 10:43 AM
31	peanuts and tree nuts not knowingly allowed in our school	12/5/2016 10:11 AM
32	no	12/5/2016 10:05 AM
33	orders and medical information is updated yearly, parents are required to provide information on sports permission forms for coaches and on field trip permission forms, students with epipen orders are not allowed to participate in out of school field trips unless they have their epipen with them	12/5/2016 9:53 AM
34	Our best practice is to make sure we have Benedryl and stock epi-pens with standing emergency orders from our school medical advisor.	12/5/2016 9:02 AM
35	reviewing the IHP with the students so they know the expectations/ goals	12/5/2016 8:58 AM
36	No	12/5/2016 8:40 AM
37	Advice staff and students to let others know of their allergies/provide safe areas in school/alert PTO of allergies when they provide snacks for after school or fund raisers	12/5/2016 7:34 AM
38	no not at this time	12/4/2016 5:15 PM
39	No	12/2/2016 7:36 PM
40	All staff have to review Sx of anaphylaxis video at beginning of school year.Lunch ladies trained. Students do not have food for parties etc...in classroom. Eating only in cafeteria except snacks. Food allergies signs in designated classrooms. District sent letter in Septmeber to all parentst about food safety.	12/2/2016 3:43 PM
41	All staff has list of children with food allergies, children bring their own snacks from home for all festivities in the class, no sharing food, peanut free table in the cafeteria, Epipens of all children are brought to the cafeteria during lunch every day.	12/2/2016 3:18 PM
42	No	12/2/2016 3:13 PM
43	Parent brings special snack for student with allergy to have on hand when there is a party etc. and can't have cupcake etc.	12/2/2016 3:04 PM
44	Training the children how to use their epipen although they are not allowed to carry it on them	12/2/2016 3:01 PM
45	Color coding allergies and making them visible to all staff members would help alert them to classroom allergies without violating privacy, then staff can stop and look up the signified and known food allergy personally. Like a visual cue that prompts a quick reference and "time out" to avoid specific students with allergies. I color code my student RED for life threatening allergies and then further frame their pic with color coded frames, brown for nut, yellow for banana, green for beans, pink for fish, ect. Just fun for me..I do obtain written consent to openly place student pics within classrooms, ect.	12/2/2016 2:40 PM
46	no	12/2/2016 2:36 PM
47	No food is allowed at school for children unless it comes from a store and is labeled with ingredients or comes from the school cafeteria. Our school does not celebrate birthdays with food and does not use food as a reward.	12/2/2016 2:01 PM
48	Every student with life threatening allergy has an IHCP and ECP.	12/2/2016 1:41 PM

49	No food sharing, try to plan non-food activities	12/2/2016 1:32 PM
50	Parents should be accountable by state law to furnish the nurse's office with the necessary epi-pens at the beginning of each school year, and should receive a consequence if they do not have one at hand on site.	12/2/2016 1:24 PM
51	AWARENESS of Students with life threatening allergies...and IHCP...	12/2/2016 1:10 PM
52	No	12/2/2016 1:04 PM
53	speaking with each child at beginning of year , reinforcing knowing there limitation, and educating the teacher,	12/2/2016 1:00 PM
54	None.	12/2/2016 12:59 PM
55	We consult with every family who has a child with a life threatening allergy, yearly to make them aware of our procedures related to food in the classroom (snack) and in the lunch room. We adapt the needs of the student depending on the conversation with their parents and their doctors orders.	12/2/2016 12:48 PM
56	We do not allow students to attend field trip without epipens and orders/plans in place	12/2/2016 12:48 PM
57	No food on the bus. Peanut free tables. No sharing allowed. Tables are washed after every seating at meals.	12/2/2016 12:42 PM
58	carry epi in ER bag	12/2/2016 12:31 PM
59	no	12/2/2016 12:29 PM
60	Having the nut free table at school	12/2/2016 11:49 AM
61	Peanut free tables work great. Some children with airborne allergies can eat elsewhere to be safe.	12/2/2016 11:38 AM
62	Teachers are made aware of their allergy with an annual email and a medical alert in the computer (Power School).	12/2/2016 11:35 AM
63	strongly recommend not sharing foods in school and a non-food reward for classroom parties (such as pencils, books, game for classroom) instead of baked goods	12/2/2016 11:30 AM
64	Hallway monitoring, cooperation and consistency of ALL staff to help with compliance, cooperation/communication between nurse and food services	12/2/2016 11:22 AM
65	Non-food celebrations	12/2/2016 11:07 AM
66	I use in the cafe for the lunch staff and cafe preparers A red book with a picture of the student their allergen and the teacher	12/2/2016 11:04 AM
67	Constant reinforcement that non-edible items should only be allowed for classroom celebrations	12/2/2016 11:00 AM
68	no	12/2/2016 10:59 AM
69	Going into classes to give a brief lesson the dangers of allergens.	12/2/2016 10:56 AM
70	Our school doesn't allow any outside food during celebrations. Classrooms with students who have severe allergies have signs on the door with the type of allergen.	12/2/2016 10:55 AM
71	All staff are Epi pen trained	12/2/2016 10:50 AM
72	Great communication with the teaching staff	12/2/2016 10:49 AM
73	Every teacher receives a confidential list of children with life threatening allergies Every teacher required to recognize and know symptoms of anaphylaxis and adm of Epi Pen Emergency medical team in school Nurse speaks to all classes about allergies several times per year	12/2/2016 10:44 AM
74	we send a letter to student's houses at beginning of school year if there are students in a classroom that should not be near peanuts	12/2/2016 10:43 AM
75	Getting permission for all ingrediants in food projects at school signed by the parents.	12/2/2016 10:42 AM
76	Our school has a "nut table" in the lunchroom so that students who bring nuts for lunch need to sit at this table. The child with the nut allergy does not feel isolated. We also have kids who eat nuts at lunch clean their hands with a wipe (no sink in lunchroom available for handwashing). The school pays for the wipes.	12/2/2016 10:41 AM
77	We emphasize teaching and guiding students towards sound self advocacy.	12/2/2016 10:36 AM
78	We do quarterly inservices and review of ECP with individual classrooms and staff members.	12/2/2016 10:35 AM
79	Due to our student age range of 3 to 5 years old our building is nut-free.	12/2/2016 10:30 AM
80	Providing confidential health alert list to teachers annually with periodic updates for new students to ensure they are aware	12/2/2016 10:22 AM

81	Make sure orders are current	12/2/2016 10:21 AM
82	We follow our Tools for Schools policy quite strictly and don't allow food in the classrooms.	12/2/2016 10:19 AM
83	No	12/2/2016 10:18 AM
84	Vigilance at all times	12/2/2016 10:08 AM
85	Gradual moving of children from allergy free tables to sitting with all their peers by teaching them to be aware of their surroundings, not eating foods from others, and cleaning their spaces and hands frequently.	12/2/2016 10:08 AM
86	Information management and training to staff re: students with life threatening food allergies.	12/2/2016 10:01 AM
87	Maintaining safe areas in lunch room for students with allergies.	12/2/2016 9:58 AM
88	Created a Activity Management Form where the school nurse must receive all food ingredients labels before allowing food into the classroom (very time consuming for the school nurse however it does keep unsafe food items out of the classroom) Allergy awareness signs in classrooms and frequent letters emailed to parents	12/2/2016 9:58 AM
89	Whenever food is provided in the classroom from anywhere other than our cafeteria the teacher is supposed to call the school nurse to come to the room to check labels for allergens/ students with known allergies.	12/2/2016 9:28 AM
90	I was instrumental in starting the town of East Hartford food services to list allergy ingredients and carbs in the monthly menus. I got the idea from the Hartford School system because they do it for all students. My daughter is anaphylactic to soy and it is good to know ingredients etc.	12/2/2016 8:26 AM
91	Educating students, parents, and teachers early in the year so that everyone is able to recognize signs and symptoms of an allergic reaction.	12/2/2016 7:50 AM
92	We have a annual med administration course for unlicensed qualified school employees	12/1/2016 5:11 PM
93	In person review of EpiPen use before every field trip	12/1/2016 12:22 PM
94	Always using caution, safety first.	12/1/2016 10:09 AM
95	Non food celebrations. If food is allowed into the classroom	12/1/2016 8:37 AM
96	No nuts allowed in classrooms with any students who have nut allergies. Nut free tables in cafeteria	11/30/2016 12:44 PM
97	No food birthday celebrations	11/29/2016 2:22 PM
98	life threatening allergies requiring life saving medications must be provided otherwise student cannot attend field trips unless MD and parent both sign statements stating student no longer has the life threatening allergy or the student does not require the life saving medication on the field trip.	11/29/2016 12:08 PM
99	no	11/29/2016 11:41 AM
100	Making individual classes Peanut and Nut Free	11/29/2016 11:31 AM
101	Identifying students by photo via assistance from the PTA, for medication administration. Color coded medication boxes storing individual's medications.	11/29/2016 11:15 AM
102	No	11/29/2016 11:02 AM
103	All staff trained to at least recognize s/s of anaphylaxis. Lots of hand washing. Letter home with class placement requesting to not send in allergen for snack consumption.	11/29/2016 10:37 AM
104	Our school strictly adheres to only allowing students with life-threatening food allergies to consume food provided by or deemed safe by their parents.	11/29/2016 10:08 AM
105	Parents are to be notified 24 hours in advance of any food served in the classroom	11/29/2016 9:57 AM
106	Asking staff to stop by my nursing office periodically to review emergency Epi-pen administration with trainers.	11/29/2016 9:49 AM
107	We post allergies in the food prep area in each classroom. using initials.	11/29/2016 9:08 AM
108	Sealed, Prepackaged foods when brought into allergy known classes for sharing	11/28/2016 3:20 PM
109	Collaboration with Cafeteria Manager and faculty	11/28/2016 1:05 PM
110	Make sure students know and can recognize 1- their allergy and 2- the symptoms of having an allergic reaction and where to seek help if one should occur.	11/28/2016 11:46 AM
111	All food brought in for classroom parties must be store bought so we can check labels and make sure nut free. No home made products allowed.	11/28/2016 11:40 AM
112	NONE	11/28/2016 11:09 AM

113	peanut/ tree nut/ allergen safe environment cafeteria food is peanut/ tree nut free	11/28/2016 9:57 AM
114	No	11/25/2016 8:59 PM
115	no	11/22/2016 9:10 AM
116	Having a current, updated school allergy list in my nurse's office, for personal use, is very helpful.	11/21/2016 11:53 AM
117	Non-food birthday celebrations	11/21/2016 10:14 AM
118	no food in the classroom	11/21/2016 10:08 AM
119	Our café staff is careful about students seating and cleaning/labeling tables for peanut exposure purposes.	11/21/2016 9:30 AM
120	CAFE IMMEDIATELY NOTIFIED OF FOOD ALLERGIES AND STAFF INPUTS ALLERGEN INTO THE COMPUTER.	11/21/2016 9:09 AM
121	Call @ the beginning of each school year to the parent's of children who had orders for Epipen the year before	11/18/2016 9:04 PM
122	Having teachers train on how to give epi-pens right before a field trip so it is fresh in their mind and having a detailed ICHP.	11/18/2016 4:08 PM
123	no	11/18/2016 3:39 PM
124	all certified staff are trained on epipen administration and signs and symptoms of anaphylaxis. There is a staff review at the beginning of every school year and a review and return demonstration performed by teachers responsible for medications on a field trip.	11/18/2016 2:07 PM
125	We ask that teachers who are expecting food in the classroom complete a form and submit it to the office so we know where to expect food in the building. It also makes teachers more aware of the need for allergy planning. Teachers must send home notification anytime food is being served or used in a classroom (science experiments), and ask parental permission or assistance in modifying the activity if needed.	11/18/2016 1:29 PM
126	Just keep calling parents to update nurse as needed when nurse has questions re allergies or need for Epipens. Notify all staff of student's allergies and reinforce as needed.	11/18/2016 1:25 PM
127	no food as reward If teacher brings in food they are responsible not RN	11/18/2016 12:55 PM
128	poster with pictures of all students with food allergy that also lists their specific allergy & if they have a medication plan. All staff view powerpoint for recognizing anaphylaxis at the beginning of each school year.	11/18/2016 11:11 AM
129	We have good collaboration with the district's food service provider regarding students with food allergies. We have developed nut free room and cafeteria protocols that are uniform throughout our school.	11/18/2016 10:43 AM
130	Continuing conferring with cafeteria and teachers regarding allergies to prevent any exposure.	11/18/2016 10:37 AM
131	We have a very inclusive policy which is consistent with our Wellness Policy	11/18/2016 10:16 AM
132	NO	11/18/2016 10:10 AM
133	no	11/18/2016 7:59 AM
134	At the end of 5th grade to middle, nurses evaluate students with an epi-pen and find what their comfort level is.	11/18/2016 7:27 AM
135	label checking and store bought	11/17/2016 3:37 PM
136	reminders to teachers, staff, educating staff and students	11/17/2016 2:37 PM
137	Nut free table- only for eating and not used any other times.	11/17/2016 2:30 PM
138	All staff should be educated on student's with food allergies and be familiar with their emergency plan	11/17/2016 2:18 PM
139	At the elementary level, if a child has a food allergy, a letter is sent home at the beginning of the year to educate parents of other kids in classroom to make them aware of the food allergy. Also, there is a no baked good policy.	11/17/2016 1:52 PM
140	No nut products allowed in any classrooms, only in cafeteria and teachers lunch room.	11/17/2016 1:38 PM
141	start early and be persistent	11/17/2016 12:33 PM
142	NA	11/17/2016 12:33 PM
143	We strive for nut-safe classrooms, have nut-safe tables in the café, have a no-food for celebrations and field trips plan at school in place.	11/17/2016 12:16 PM

144	We have "allergy awareness" rooms. Because I have as many egg, milk, legume, gluten allergies as I do peanut/tree nut allergies, we classify rooms as "allergy aware". Letters go home in the summer packets with those specific foods highlighted. All food for those rooms is checked by me when it comes in, prior to going into class. Celiac kids are covered by 504 plans also. I always encourage "no food" celebrations and many teacher choose to do this in their classroom. They do extra recess on birthdays, "princess/prince" for the day, teacher's helper etc.	11/17/2016 11:59 AM
145	Non food celebrations in school.	11/17/2016 11:58 AM
146	No shared birthday treats coming in allowed anymore as per policy	11/17/2016 11:43 AM
147	No	11/17/2016 11:27 AM
148	Nut-free classrooms and having a "No Nut" table in the cafeteria for lunch..	11/17/2016 10:58 AM
149	During my inspections of food for parties I ran into many parents totally clueless on reading labels. I educated parents, families, kids, and staff. This changed awareness in a big way. Many mad parents, crying students, and mad staff before they ultimately changed the no party food policy. Realizing a healthier non stressed school. A lot of parents were relieved. Many people thanked me for educating on food allergies, reading labels, cross contamination meaning. And how to protect kids at snack time, cleaning procedures of hands and furniture. ALL my staff know the sign and symptoms of allergic reactions and teachers can demonstrate how to give the EPI.I give a cartoon of S&S for parents to keep on frieg and tell them to write allergy at top and their address for babysitters who will freak out and not remember the address if it happens. When a new student comes ask multiple questions including all the S&S of food allergies. Some parents don't connect the dots. A lot of food intolerances as well. Dairy is the biggest ones.	11/17/2016 10:41 AM
150	The above as stated which has been very successful here at this elementary school	11/17/2016 10:32 AM
151	education is key.	11/17/2016 9:55 AM
152	Classroom and student education and responsibility.	11/17/2016 9:46 AM
153	I would like to see non food items brought in for celebrations and birthdays. I feel bringing in items from home is too much risk and liability. Parents often go by their own rules and as nurses we are so often forced to police on top of all our other important daily assignments.	11/17/2016 9:41 AM
154	I put a caution sign outside each classroom of a student that has a food allergy It says check with teacher before entering with food	11/17/2016 9:38 AM
155	Containing food celebrations in classroom where know foods served have no students with sensitivities or allergies	11/17/2016 9:37 AM
156	As 99% of our life threatening allergies have been nuts, the only place nuts are allowed in the building are in the cafeteria and the teacher lounge. All other classrooms are nut free. Thus students must bring in safe foods for snack time that are consumed in the classroom.	11/17/2016 9:21 AM
157	Allergy list of students is reviewed monthly and changes communicated to teachers.	11/17/2016 9:11 AM
158	no celebrating with food ,talk with staff members about individual students with life threatening allergies and discussing preventative plan and emergency plan	11/17/2016 9:08 AM
159	No baked goods from home-	11/17/2016 9:08 AM
160	Use soap and water to clean your hands after eating a nut product, not purell; reinforce the no sharing of food with friends	11/17/2016 9:08 AM
161	Every student has an Emergency Plan on file - a 504 and IHCP is not needed but the Emergency Plan is generated for all students.	11/17/2016 9:04 AM
162	no	11/17/2016 8:59 AM
163	Teaching about allergies/epinephrine	11/17/2016 8:54 AM

Q16 What are your biggest challenges to ensuring the safety and inclusion of students with life-threatening allergies?

Answered: 281 Skipped: 192

#	Responses	Date
1	Inconsistency in information provided by guardian and health care provider. Lack of a registered dietitian to identify and provide safe food choices for students with known food allergies.	12/7/2016 1:19 PM
2	None at this time.	12/7/2016 12:47 PM
3	Educating the staff.	12/7/2016 12:32 PM
4	there is a nut and peanut free policy in the classroom but not in the cafeteria or for field trips. the cafeteria provides peanut butter and jelly for field trips to all kids who buy lunch. also, parents bring in unlabeled or home baked goods to class for class wide celebrations	12/7/2016 11:47 AM
5	Communication with parents and doctors to obtain up to date orders and medications.	12/7/2016 11:45 AM
6	food brought in from home and celebration times where food is hard to control. Birthdays, holidays etc.	12/7/2016 11:34 AM
7	Parent's ability to pay for medication.	12/7/2016 11:20 AM
8	School wide events that admin/PTA serve food at and nurse not aware this is going on. Per a parent's request, having an entire grade in middle school not able to have a snack despite a very late lunch and dealing with the difficulty with pushback from staff and parents. Biggest problem is the school administration allowing food into classroom be a negotiable option. This leads to inconsistencies with teachers and confusion as to what the policy really is. A guideline given by admin of sending home a note informing parents that food will be served or part of a project is not followed by all teachers and is not enforced by admin.	12/7/2016 11:15 AM
9	1) Doctors not completing forms in their entirety 2) Parents not bringing forms and/or med to school	12/7/2016 10:49 AM
10	"Treats" from other students for celebrations. Hard to "alienate" a student - so they are required to be peanut/treenut or allergen free. Worrisome to ensure.	12/7/2016 10:45 AM
11	The biggest challenge is having to be in touch with at least half the parents every year to remind them that we need an updated order and epipen each school year; many do not follow through. It seems that many parents and children do not take this seriously.	12/7/2016 10:26 AM
12	parents unable to provide medical documentation and/or medications to health office in a timely manner	12/7/2016 10:05 AM
13	Outside food is allowed to be brought into classrooms.	12/7/2016 9:48 AM
14	use of school buildings for public programs after hours	12/7/2016 8:59 AM
15	My biggest challenges are having staff trained and willing to use Epi-Pen and having parents comply w/ the food safety rules.	12/7/2016 8:53 AM
16	When staff/students bring in items to share that are allergens. Although our Allergy Management Plan discourages treats, they are still brought in occasionally. And although not food allergy, latex balloons continue to be of concern as staff seem to forget how serious latex allergies are and allow balloon arches at dances etc.	12/6/2016 12:37 PM
17	Food sharing Team breakfast/lunches	12/6/2016 12:05 PM
18	lack of education	12/6/2016 11:45 AM
19	Parents that do not follow through with getting updated orders on file to use an epipen and the students that do not follow their own health plan	12/6/2016 11:28 AM
20	educating materials not only for the students but for the staff. It is very difficult to make them understand the importance of being Nut Aware and as much as possible being Nut Free	12/6/2016 10:38 AM
21	outside treats for birthday celebrations	12/6/2016 9:31 AM
22	That they stay away from the allergen, they are little so they don't yet think of it.	12/6/2016 9:17 AM
23	parents sending in medications in a timely manner.	12/6/2016 8:44 AM

24	communication/doctor's orders/med from parents	12/6/2016 8:28 AM
25	Inclusion with snacks and parties	12/6/2016 8:13 AM
26	Obtaining EpiPens from parents and medical administration authorization	12/6/2016 7:57 AM
27	none currently	12/6/2016 7:29 AM
28	Parents notifying school staff and/or follow through obtaining medications (cost may affect purchase)	12/6/2016 7:29 AM
29	having medication and a signed doctor's order to administer	12/5/2016 4:39 PM
30	Getting parents to bring in orders and Epi pens in a timely manner. When a parent tells the school nurse their child is no longer allergic to a certain food and then does not bring in MD documentation to support this.	12/5/2016 3:39 PM
31	Although district does not have a policy on allergy prevention, district does have a Wellness Policy which suggests avoiding food in classroom celebrations. At our school we have instituted a no food practice for classroom celebrations and it has been helpful.	12/5/2016 3:35 PM
32	Parents continue to use food as the premier reward/celebratory medium. They also bring in food without the requested ingredient list.	12/5/2016 2:26 PM
33	To make sure the student is carrying his/her epi-pen at all times and that the teachers are aware of where the epi-pen is kept e.g field trips, I always ask the teachers to check if the student has his/her epi-pen and where the student is keeping it, eg backpack	12/5/2016 2:11 PM
34	controlling food brought in from outside	12/5/2016 1:49 PM
35	Parents obtaining Epi-Pens and orders from the PCP. can be a problem. Also, we have students who should be re-tested or have further testing for their allergies. We have students who say they are not allergic anymore or parents that say their child doesn't have a problem anymore but are not having their child retested to discontinue the Epi-Pen order.	12/5/2016 1:46 PM
36	Those that cannot afford the epiPens- we have a difficult time getting them for school.	12/5/2016 1:38 PM
37	The biggest challenge is the large lunch waves with many students and only 2 adults to watch over the many students.	12/5/2016 1:09 PM
38	In the HS the students reading labels or asking what is in the foods he eats	12/5/2016 12:43 PM
39	outside food sources	12/5/2016 12:23 PM
40	Food (snacks, lunches) brought to school	12/5/2016 12:17 PM
41	Not all parents send in epi-pens and/or MD orders. Not all parents can afford to buy epi-pens or do not understand the safety hazards of not having one for diagnosed conditions.	12/5/2016 12:16 PM
42	food sharing between students	12/5/2016 12:16 PM
43	Food being brought into the school by parents for food celebrations.	12/5/2016 12:07 PM
44	At the beginning of the school year, getting all parents to bring in the EpiPen and med authorization.	12/5/2016 11:54 AM
45	Parents not bringing the medication in or not replacing expired medication. Food celebrations that are part of a lesson plan.	12/5/2016 11:44 AM
46	My school allows parents to bring in homemade treats. I worry a food allergic child may accidentally ingest an allergen	12/5/2016 11:33 AM
47	Keeping them symptom free	12/5/2016 11:14 AM
48	food in the elementary school classroom	12/5/2016 10:51 AM
49	My school is not peanut free.	12/5/2016 10:45 AM
50	Unsure	12/5/2016 10:43 AM
51	reminders to parents not to send in foods with peanut and tree nuts;	12/5/2016 10:11 AM
52	instruction of teaching staff	12/5/2016 10:05 AM
53	food brought from home by students and teachers, non-compliance of students, parent cooperation to get doctor orders/medication	12/5/2016 9:53 AM
54	Getting parents to provide medication orders and the medication.	12/5/2016 9:03 AM
55	getting parents to bring in doctor orders and prescription medication: Benedryl and Epi-pens. Parents can't afford it and rely on the schools to provide emergency epi-pens. Some send in doctor orders and no medications.	12/5/2016 9:02 AM

56	the students need to take their allergies seriously	12/5/2016 8:58 AM
57	Students who travel to and from school without emergency medication	12/5/2016 8:40 AM
58	Safety: none with age group we work with inclusion: celebration parties, put on by outside groups that involve food	12/5/2016 8:05 AM
59	Staff and students who are not conscious of how they can prevent an allergic reaction of others	12/5/2016 7:34 AM
60	student being aware of food ingredients	12/4/2016 5:15 PM
61	Cafeteria food	12/2/2016 7:36 PM
62	That all students washed their hands before and after eating in the cafeteria	12/2/2016 3:43 PM
63	having non allergic students bringing in snacks and lunches that are not safe for their classmates	12/2/2016 3:25 PM
64	Some parents take time to bring medication to school	12/2/2016 3:18 PM
65	Not enough information. Ignorance.	12/2/2016 3:13 PM
66	Monitoring the Peanut free lunch table Monitoring special snacks provided by parents for birthday parties, etc.	12/2/2016 3:04 PM
67	My concern is getting to a child on the opposite side of the school with their epi pen during Anaphylaxis. Teachers aren't allowed to keep epipens in their classrooms and aren't allowed to give epi pens unless trained and on a field trip.	12/2/2016 3:01 PM
68	Field trips	12/2/2016 2:53 PM
69	Not having all staff aware of students with allergies staff not reading ingredients parents unsure if allergy is life threatening or just an isolated or minor allergic episode.	12/2/2016 2:40 PM
70	sharing and/or exposure to allergens in foods brought in from home	12/2/2016 2:36 PM
71	School parties create the biggest challenge to keeping students safe, especially in the elementary schools. The time and energy it takes to ensure that no harmful foods are brought in to the classroom is exorbitant	12/2/2016 2:27 PM
72	Field Trips	12/2/2016 2:07 PM
73	Helping kids to be there best advocate without making them feel singled out.	12/2/2016 2:01 PM
74	Getting some parents to get a signed medical form for and Epi-Pen and bringing in medication.	12/2/2016 1:55 PM
75	Having parents provide medication in a timely manner	12/2/2016 1:41 PM
76	We do have a nut free policy, however parents without children with nut allergies do not have the understanding severity of allergies.	12/2/2016 1:32 PM
77	Diagnosed students with life threatening allergies do not have Epi pens in school	12/2/2016 1:24 PM
78	Getting parents to bring in required paperwork and medications.	12/2/2016 1:23 PM
79	We are a "nut safe" district, not "nut free". Parents bringing/sending foods into the classroom even though a statement about "Life threatening allergies" at school is sent home at the beginning of the school year	12/2/2016 1:21 PM
80	Parents/Caregivers not always carefully reading ingredients for snacks	12/2/2016 1:19 PM
81	Occasionally a child might not have someone to sit with at peanut free table, although efforts are made to remedy this situation.	12/2/2016 1:11 PM
82	That they themselves are well aware of their allergens, and are diligent in avoiding them...	12/2/2016 1:10 PM
83	All my plans are in place-doctor's order's and medication are at school- I feel students are safe with a known or unknown allergy	12/2/2016 1:06 PM
84	Children sneak food in an share with others.Teachers still think a food treat as reward is ok...even with repeated education .	12/2/2016 1:04 PM
85	children forgetting to look at labels and eating shared foods,	12/2/2016 1:00 PM
86	Obtaining the correct orders and plan from the Pediatrician.	12/2/2016 12:59 PM
87	children sharing food	12/2/2016 12:51 PM
88	Compliance of parents, underestimating the life threatening aspect of anaphylaxis	12/2/2016 12:48 PM
89	Making sure that parents do not send or permit their child to bring food allergens to school.	12/2/2016 12:42 PM
90	Students who accidentally share a food.	12/2/2016 12:42 PM

91	PTA giving treats during school day as part of a celebration. Classroom teachers who act like they never knew about district policy when it has been gone over several times. Eating lunch in classrooms if lunchroom is being used for other purposes.	12/2/2016 12:35 PM
92	Being aware of the allergies	12/2/2016 12:31 PM
93	education of both parents of allergic and non allergic children	12/2/2016 12:29 PM
94	complete understanding of issue from the stand point of those not affected by this issue	12/2/2016 12:06 PM
95	getting parents and guardian to bring in medications and having them respond to calls and notes sent home.	12/2/2016 11:49 AM
96	When food is given as "treats" in the class room without checking with the nurse.	12/2/2016 11:49 AM
97	Making sure there the trained staff member is available when the nurse may be out	12/2/2016 11:45 AM
98	Epi pen costs, parents bringing in epi pen and orders, and cooperation with families/school.	12/2/2016 11:38 AM
99	At the high school, our biggest challenge is to make sure parents understand the importance of maturing students taking responsibility to self-advocate in avoiding their allergen.	12/2/2016 11:35 AM
100	Age related issues at elementary level for food avoidance and identification. Communication and adult follow through outside of Health Room	12/2/2016 11:31 AM
101	Food celebrations.	12/2/2016 11:31 AM
102	Field trips away from school and trained staff for coverage	12/2/2016 11:30 AM
103	Staff and students who bring in/eat foods that are unsafe without the consent or knowledge of the staff here at school	12/2/2016 11:22 AM
104	getting the medications and medication authorizations from the parents	12/2/2016 11:13 AM
105	Outside snacks brought to school for various school celebrations	12/2/2016 11:07 AM
106	Teachers attempting to have food/'treats' at celebrations 'under the radar' without following school policies; evening school-wide events	12/2/2016 11:07 AM
107	getting parents to bring in the prescribed medication and authorization/emergency plan in a timely manner	12/2/2016 11:06 AM
108	classroom parties are a nightmare. Items baked at home, even if they do not contain the allergen, can be cross-contaminated in the cooking process, and it is inconvenient for parents of allergic students to provide alternative treats for last minute gatherings. Even sending in an alternative treat for the allergic child still separates them from participating like every other child in the classroom. Food free classroom celebrations would be much better.	12/2/2016 11:05 AM
109	cafeteria food and the staff they hire to adhere to cross contamination and student identification with allergies guidelines can be a problem Snacks in the classroom . NO soap and water in the classrooms (old building)	12/2/2016 11:04 AM
110	By just omitting an allergen in a school, a false sense of security may be given. Many products may contain an ingredient that a student has an allergy to, unless label reading is done on every item. Good handwashing, cleaning of surfaces is essential to cross contamination. Limiting exposure to an allergen is another important measure to prevent anaphylaxis. Passing of laws that cannot be completely followed through with is one of the biggest challenges for schools.	12/2/2016 11:02 AM
111	Celebration foods	12/2/2016 11:00 AM
112	No strict consequences for bringing non-edible items fro classroom celebrations	12/2/2016 11:00 AM
113	lack of control food from home and other parents	12/2/2016 10:59 AM
114	Receiving the required paperwork and meds for students identified as having allergies	12/2/2016 10:58 AM
115	Snacks on the bus.	12/2/2016 10:56 AM
116	I sometimes have to make several calls to parents requesting the EpiPen and MD order.	12/2/2016 10:55 AM
117	other students bringing in food to share. Celebrations should be non food oriented	12/2/2016 10:54 AM
118	Getting the paper work and medication form the parents	12/2/2016 10:50 AM
119	none	12/2/2016 10:49 AM
120	students bringing peanuts into the classroom	12/2/2016 10:43 AM
121	We have permission slips to fill out anytime food is being brought in for a special activity but sometimes parents still bring food in and are told that we can't hand it out. Sometimes we find out after the fact that food has been brought in and handed out by teachers by children after the fact.	12/2/2016 10:42 AM

122	Education of parents and staff. Compliance and knowledge of younger students. Getting other parents to understand.	12/2/2016 10:41 AM
123	They are high school students who may not make the best choices during the day.	12/2/2016 10:37 AM
124	Timely dissemination of information to staff at start of school year with new entrants/diagnoses	12/2/2016 10:36 AM
125	We are a nut sensitive school and it is a challenge to monitor the compliance to the no nut rule. additionally many of our children have PICA.	12/2/2016 10:35 AM
126	I wonder if all students who have allergies have been identified to the school by either the parent or pediatrician	12/2/2016 10:34 AM
127	Parents providing Dr.'s order or medication by first day of school, or mid year	12/2/2016 10:30 AM
128	Getting the medication authorization and medication from parents. Ensuring the staff is aware and remembers which student have life threatening allergies.	12/2/2016 10:22 AM
129	Denial that there is an allergy Not wanting to let others know	12/2/2016 10:21 AM
130	educating parents of children without live threatening allergies of the seriousness of issue and need for policies in school	12/2/2016 10:20 AM
131	Parents who do not follow through with obtaining epipen orders or go see and allergist to be sure there is a true life threatening allergy.	12/2/2016 10:19 AM
132	none	12/2/2016 10:19 AM
133	Getting parents to comply with providing health care providers' allergy management plans, medication authorizations, and bring in the medication to school. Fortunately, this is only a small percentage of parents.	12/2/2016 10:18 AM
134	Prevention of students sharing food and bringing in food that others are allergic to	12/2/2016 10:11 AM
135	getting the plans signed, distributed, teachers informed , FIELD TRIPS	12/2/2016 10:09 AM
136	I don't feel there are challenges	12/2/2016 10:08 AM
137	Parents who won't teach their children to be safe and aware of their surroundings.	12/2/2016 10:08 AM
138	Field trips	12/2/2016 10:04 AM
139	Staff taking individual steps in the classroom without be familiar with this districts policies.	12/2/2016 10:04 AM
140	Parents sending outside food for in school celebrations.	12/2/2016 10:02 AM
141	Compliance of parents to provide medication. Need frequent reminders and physician contact.	12/2/2016 10:01 AM
142	recognition of other students and cross contamination	12/2/2016 10:01 AM
143	Our plan seems to be working very well.	12/2/2016 9:58 AM
144	Food sources entering the building for parties Parental compliance in keeping food items safe for all students	12/2/2016 9:58 AM
145	For those with diagnosed conditions in our school everyone is aware of the child from kitchen to staff, Pictures are posted etc. biggest problem is where to store epipens. I would like not to keep them in the Office, but in red bags that teachers in our building take everywhere.This includes outside, fire drills evacuations .	12/2/2016 9:40 AM
146	there are many snacks brought to school and passed around and are a temptation to students with food allergies.	12/2/2016 9:32 AM
147	classroom parties that include food	12/2/2016 9:28 AM
148	Education	12/2/2016 9:16 AM
149	Follow through.Parents and MD list allergy. Parent does not provide medication	12/2/2016 8:30 AM
150	Having the staff communicate with nurse if they bring food in so we can look at ingredients etc. A lot of the time, teachers think everything is safe when it is not. For instance, if someone is allergic to soy- soy oil is found in most foods etc.	12/2/2016 8:26 AM
151	getting the EpiPens and orders into school	12/2/2016 8:08 AM
152	Getting orders signed by medical providers by the first day of school	12/2/2016 7:50 AM
153	Parents not supplying epi	12/1/2016 5:11 PM
154	Parents of students without allergies don't understand the seriousness of a life threatening allergy. They continue to send food with allergens to classroom events even after notifications have been sent regarding the life threatening allergy.	12/1/2016 12:32 PM
155	teachers, parents, and other staff bringing in outside food and giving to the children	12/1/2016 12:30 PM

156	Getting accurate information to students, parents and staff. Preventing lackadaisical attitude towards allergy prevention.	12/1/2016 12:22 PM
157	Cultural, foreign language, food parties, and reminding staff and student's to be mindful of ingredients and to share the recipes, so others are aware. Student's who will bring common allergy foods to school.	12/1/2016 10:09 AM
158	available epi pen and staff knowledge of emergency plans for those with know reactors and unknown reactors	12/1/2016 9:50 AM
159	Parents not following policy	12/1/2016 8:37 AM
160	Birthday parties at school.	11/30/2016 12:44 PM
161	Holiday celebrations	11/29/2016 2:22 PM
162	getting the medication and forms from parents and doctors	11/29/2016 12:08 PM
163	Parent not bring in med.	11/29/2016 11:41 AM
164	when there is food brought in from the outside for celebrations. This year our district has eliminated food for birthday celebrations which is a great first step but food is still allowed for the Halloween party and the Thanksgiving feasts.	11/29/2016 11:39 AM
165	Cupcake and treats brought to school for birthdays and celebrations	11/29/2016 11:31 AM
166	Educating students about their allergies as well as teachers and avoiding exposure to allergens.	11/29/2016 11:30 AM
167	To get other family and kids more aware that students have allergies especially during parties and class trips	11/29/2016 11:21 AM
168	Food is still brought into the school at times without the nurse's knowledge.	11/29/2016 11:19 AM
169	Self education of condition and actualization of the action plan	11/29/2016 11:15 AM
170	Staff and other students THINK before have allergens for themselves. They need constant reminders.	11/29/2016 11:02 AM
171	The various allergens, parental compliance which is often impacted by the cost of the medication	11/29/2016 10:37 AM
172	teachers using food items in their curriculums.	11/29/2016 10:20 AM
173	Parents bring in the medication& forms to school do to expense of both	11/29/2016 10:19 AM
174	Getting parents to bring in new MD authorization for medications at the beginning of the school year. Also, getting parents to bring in medication the first day of school.	11/29/2016 10:17 AM
175	Celebrations that involve food, especially at holidays.	11/29/2016 10:08 AM
176	Celebrations that include food with unknown ingredients	11/29/2016 9:57 AM
177	Getting parents to submit appropriate documentation at the beginning of the year and providing epic-pens to school with sustained shelf life and not about to expire...	11/29/2016 9:49 AM
178	Noncompliance & poor follow through of parents. Food (cupcakes, etc.) brought into school by students & teachers.	11/29/2016 9:25 AM
179	Parents not sending in the medications or having med forms filled out in a correct and timely manner.	11/29/2016 9:15 AM
180	students are non verbal and cognitively impaired	11/29/2016 9:08 AM
181	checking foods for sharing during a celebration time	11/28/2016 3:20 PM
182	Food being brought in from outside sources	11/28/2016 1:05 PM
183	Student's themselves- I've had a few students in the past few weeks knowing they are allergic to a certain food still eat it because they "were hungry". These were non-life threatening reactions Also parents who know their child has a life threatening allergy and do not supply the school with an epi-pen, even after nurse has contacted and educated them on the importance.	11/28/2016 11:46 AM
184	Our school has peanut free rooms for safety of children but it is a challenge with some parents that don't agree with these measures.	11/28/2016 11:40 AM
185	NONE	11/28/2016 11:09 AM
186	Because the school is not peanut/ tree nut free, it is important for students in classrooms to be especially careful with food celebrations and snacks that may contain peanuts or tree nuts	11/28/2016 9:57 AM
187	parent compliance with bringing epipen to school	11/28/2016 8:41 AM
188	Reminding teachers to ask for ingredients.	11/25/2016 8:59 PM
189	making sure parents let nurse know/bring in epipen to school. making sure teachers limit known allergic foods in classroom,especially at parties.	11/24/2016 9:10 AM

190	Making sure we have identified all students with life-threatening allergies as parents do not always report them to us.	11/23/2016 11:09 AM
191	Field trips, the teachers are not always in close quarters. Although they are all trained, I worry especially @ amusement parks!	11/23/2016 8:17 AM
192	Outside food being brought in to the school setting	11/22/2016 12:26 PM
193	Making sure the epipen and allergy plan follows the student's activities/classes during the school day.	11/22/2016 10:50 AM
194	Holiday parties and class field trips - making sure that the student will not eat something that they are allergic to.	11/22/2016 10:16 AM
195	exposure to allergin	11/22/2016 9:10 AM
196	The biggest challenge I feel is when teachers or parents bring in food and the nurse if not notified.	11/21/2016 1:59 PM
197	Parental compliance with bringing in EPI in student's with known anaphylaxis. Staff compliance with the "no shared food brought into school rule"	11/21/2016 11:53 AM
198	Food brought in for parties and celebrations.	11/21/2016 10:41 AM
199	N/A	11/21/2016 10:14 AM
200	celebrations	11/21/2016 10:08 AM
201	Our students regularly take community trips, and we need to be mindful about options/menus at local restaurants.	11/21/2016 9:30 AM
202	Parents/students do not understand the severity of anaphylaxis or bringing in an EpiPen to school.	11/21/2016 9:14 AM
203	FOOD BROUGHT IN TO THE SCHOOL FOR BIRTHDAY CELEBRATIONS.	11/21/2016 9:09 AM
204	Receiving updated yearly physician's orders along with the medication	11/18/2016 9:04 PM
205	Getting some teachers on board with following the school classroom management plan. Parents who bring impromptu snacks/treats into the classroom. Food label reading.	11/18/2016 4:27 PM
206	parent non-compliance with bringing in epipens. not having stock epi-pens.. instead we have epineprine in ampules which would take away precious moments of life saving time because it takes time to draw up the medication with a filter straw and then switch to IM needle.	11/18/2016 4:08 PM
207	food brought into school for celebrations	11/18/2016 3:39 PM
208	Time for adequate training of staff	11/18/2016 2:53 PM
209	food celebrations in classrooms	11/18/2016 2:07 PM
210	Communicating to all staff the significance of the allergy.	11/18/2016 1:51 PM
211	An increasing number of families are not providing epipens to school because of cost. With costs on the rise and a very short shelf life many families are just not financially able to keep getting them every year. Although we do have one stock epipen, it still poses a safety risk for students--especially for field trips. Some parents are just opting to exclude their children from a trip for their safety.	11/18/2016 1:49 PM
212	Outside foods and treats being brought in to the school for celebrations by staff, family and friends.	11/18/2016 1:33 PM
213	Parental follow through providing meds and authorizations. After school events such as sports, dances, etc.	11/18/2016 1:29 PM
214	When the students eat certain foods in class and other students in class are allergic to it. when they spray cologne or perfume in class when others are allergic.	11/18/2016 1:26 PM
215	The educational department gives student food rewards that are not necessary, should be gifts instead like pencils, erasers, etc.. Parents forget to update nurses of new allergies or send in Epipens for life-threatening allergies. More students need to be tested by Allergists when students are suspected of allergies or go to ER for allergic reaction.	11/18/2016 1:25 PM
216	Food being brought into school from home. Class/school parties with food.	11/18/2016 1:19 PM
217	private school makes numerous accommodations for students with food allergies- probably the biggest challenge is the risk of cross contamination from other students who may not know the risks	11/18/2016 1:03 PM
218	staff bring in food from home	11/18/2016 12:55 PM
219	Parent/student/teacher compliance with the plan	11/18/2016 12:20 PM
220	misinformation regarding food safety and denial of the severity of the allergy	11/18/2016 11:11 AM
221	Field Trips that offer food as part of the activity! School celebrations where food is involved, i.e. end of year picnic, specific holidays	11/18/2016 10:43 AM

222	Monitoring what the other children bring to school to eat.	11/18/2016 10:37 AM
223	classroom parties	11/18/2016 10:27 AM
224	parents/guardians supplying signed medication administration forms and supplying medication for life-threatening allergies	11/18/2016 10:23 AM
225	Getting parents to bring in medication orders and the actual epipen	11/18/2016 10:16 AM
226	Parent participation and understanding that an Epi Pen is necessary.	11/18/2016 10:10 AM
227	food rewards and celebrations	11/18/2016 9:25 AM
228	Cooperation of parents in getting plans from the doctors/care providers	11/18/2016 8:56 AM
229	making sure the students with food allergies do not take food from classmates without making sure there are no allergens in the foods while in the lunchroom or on field trips.	11/18/2016 7:59 AM
230	The biggest challenge is to have students carry their own epi-pens especially in middle and high school.	11/18/2016 7:27 AM
231	school policy to enable outside food for special occasions	11/17/2016 3:37 PM
232	bake sales, parties	11/17/2016 2:37 PM
233	Greatest challenge is food comes in from home everyday. Nut free processing changes so frequently.	11/17/2016 2:30 PM
234	Food brought in to school by other families for parties, birthdays, etc.	11/17/2016 2:18 PM
235	Parents who send in snacks with nuts into a classroom that is nut free	11/17/2016 2:18 PM
236	Parents not sending in orders and epipens	11/17/2016 2:02 PM
237	Holiday celebrations with home made foods.	11/17/2016 1:55 PM
238	Exposure to other kids & staff using food as an award and to interact with kids	11/17/2016 1:52 PM
239	Classroom parties with food.	11/17/2016 1:38 PM
240	Getting both the medication and orders in school in a timely fashion.	11/17/2016 1:03 PM
241	Food entering school for parties/ birthday celebrations. Communication between multiple staff members, subs. Naivete among staff/ parents regarding the severity of food allergies.	11/17/2016 12:51 PM
242	obtaining compliance from parents MD's regarding orders and medication	11/17/2016 12:33 PM
243	NA	11/17/2016 12:33 PM
244	The cost of Epipen has resulted in many parents postponing obtaining an Epipen at school until it is required (i.e. for field trips.)	11/17/2016 12:16 PM
245	Keeping the nut free classrooms/cafeteria safe from food that is brought in by other students/parents and other outside food sources	11/17/2016 12:01 PM
246	My school is not a "peanut/nut free" school. We do allow safe foods for parties but NO baked goods from home EVER. My teachers and I work as a team and we do a great job. The hardest thing is "all school" events and those parents who do not follow the rules and I have to send food home as unsafe.	11/17/2016 11:59 AM
247	Food celebrations in school are dangerous for food allergy students.	11/17/2016 11:58 AM
248	Staff don't always comply with plan. Administrators don't enforce plan.	11/17/2016 11:55 AM
249	Food coming in. Lunch time.	11/17/2016 11:43 AM
250	The unpredictability of small children and the risk of food sharing.	11/17/2016 11:37 AM
251	Students sharing food.	11/17/2016 11:27 AM
252	We don't have any problem with this at the high school level.	11/17/2016 11:27 AM
253	having them ALL bring in medication/paperwork - hate having to chase them down.	11/17/2016 11:26 AM
254	Our biggest challenge is the amount of food celebrations that occur in the school.	11/17/2016 11:24 AM
255	Food brought in by parents without notice and some staff who offer food/treats despite policy to promote non food celebrations.	11/17/2016 11:23 AM
256	lack of control when child is out of nurse range	11/17/2016 11:03 AM

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257	Making sure everyone in contact with our anaphylactic students, in school, are on "the same page" with anaphylactic policy/procedure	11/17/2016 10:58 AM
258	It used to be parties at school. But I would insist on seeing and reading all food labels prior to food going into classes.	11/17/2016 10:41 AM
259	Just making sure these students don't share food or eat food that they are allergic to.	11/17/2016 10:33 AM
260	have nut safe school --after communicating to parents /children info R/T life threatening allergies they have been completely supportive of this policy for over 5 years. --will continue to implement & inform so that all students can be safe.	11/17/2016 10:32 AM
261	trying to have parents of non allergic children understand the importance of following the food allergy protocols in nut aware classrooms.	11/17/2016 9:58 AM
262	Keeping the food at class parties at a minimum.	11/17/2016 9:55 AM
263	Field trips and after school activities	11/17/2016 9:46 AM
264	Classroom celebrations with food	11/17/2016 9:46 AM
265	Parents following the rules regarding the foods they send into schools.	11/17/2016 9:41 AM
266	The Epi- opt out letter to parents challenges the safety of our students	11/17/2016 9:40 AM
267	Snack choices in classrooms	11/17/2016 9:40 AM
268	classroom parties	11/17/2016 9:38 AM
269	Students sharing foods, food celebrations	11/17/2016 9:37 AM
270	Getting the parents/guardians to get the orders and medication into school. Getting Practicioners to write for self administration of Epi-pen in high school.	11/17/2016 9:35 AM
271	food brought in for "parties/celebrations"	11/17/2016 9:25 AM
272	Parties and food brought into the classroom /cafeteria for celebrations	11/17/2016 9:22 AM
273	Educating parents, staff and students who do have experience with this issues.	11/17/2016 9:21 AM
274	staff having food related parties or class activities.	11/17/2016 9:14 AM
275	Baked goods coming in to the school for Birthday Celebrations.	11/17/2016 9:11 AM
276	staff giving food to students,students sharing food	11/17/2016 9:08 AM
277	Not many. We try to eliminate allergens all together and allow for choices to include all students	11/17/2016 9:08 AM
278	families and students understanding of their plan; students sharing food in the cafe, we are a no peanut kitchen, but kids will share rarely resulting in a food allergy reaction	11/17/2016 9:08 AM
279	Students who are designated as self carry actually carrying medication with them at all times.	11/17/2016 9:04 AM
280	Children who do not bring in epipen permission form from the Dr.	11/17/2016 8:59 AM
281	Having parents respond with medication orders & plan	11/17/2016 8:54 AM

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Q18 Any other comments that you would like to share?

Answered: 91 Skipped: 383

#	Responses	Date
1	Problems: there are several food and non allergies that also require management. the only district policy is based on peanuts/nuts.also, we do not have a mandate for parents to supply us with medical plans and epipens.	12/7/2016 11:47 AM
2	Not at this time	12/7/2016 11:34 AM
3	Parents expect a lot from the school, ,but then they take their kid to a fast food place????	12/7/2016 10:45 AM
4	ensure there is a nut free food service	12/6/2016 11:45 AM
5	Educating the student with food allergies about their allergy and importance of never sharing food is very important and effective in prevention of a reaction.	12/6/2016 10:36 AM
6	504s are a work in progress. By the end of the year last year all but 3 were completed.	12/6/2016 8:44 AM
7	no	12/6/2016 7:29 AM
8	On the question that asks if we have a food allergy prevention and management plan for our district, I'd like to clarify that our district does not have a district wide prevention plan protocol, but we do have clear standing orders for Anaphylaxis which is the management portion, so I was not able to fill out the next question clearly.	12/5/2016 3:39 PM
9	I find that in many cases when a food allergy is identified with a plan that the students relate use of these very foods at home frequently by other family members!	12/5/2016 2:26 PM
10	I have one student that "used to have" a bee sting allergy, mom said she was stung this summer and had very little reaction. Up until this year I had a parent/doctor med adm. form and epi pen was supplied to school. I believe the increased cost of the epipen is why the parent is denying her allergy now. I have stock pens and standing orders so am not concerned, but this is a child I know, just worried about getting a student that the parent does not share that information.	12/5/2016 1:49 PM
11	The cost of Epipens has impacted our ability to get family to provide Epipens to school.	12/5/2016 12:16 PM
12	I am a new school nurse and not sure of all of the information provided - it was answered to the best of my knowledge.	12/5/2016 12:02 PM
13	Food should not be used as treats or rewards. I have been working on developing an atmosphere of nonfood celebrations with my principal	12/5/2016 11:33 AM
14	None.	12/5/2016 10:43 AM
15	I work in a private school which makes our policy a little easier to enforce.	12/5/2016 10:11 AM
16	no	12/5/2016 10:05 AM
17	Our school is in the process of providing 504 plans for all students with life-threatening allergies.	12/5/2016 9:03 AM
18	Senator Blumenthal is trying to get Merck Pharmaceuticals to stop price gouging. Is there another company that makes auto-injectors that is an appropriate competition for Merck?	12/5/2016 9:02 AM
19	I would recommend that there be some policy that allows emergency meds to travel on school buses	12/5/2016 8:40 AM
20	Found that students in middle school try foods offered by friends without checking the labels!!	12/5/2016 7:34 AM
21	no not at this time	12/4/2016 5:15 PM
22	No	12/2/2016 7:36 PM
23	Parent have option to opt out the "peanut free table". Some student are eating lunch with their peers who might have allergens in their lunch.	12/2/2016 3:43 PM
24	No	12/2/2016 3:13 PM
25	No	12/2/2016 3:04 PM
26	no	12/2/2016 2:36 PM

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27	I would like to see a state wide standardized emergency form/medication authorization form to prevent any confusion regarding order of medication administration. Very often the way the doctor's order is confusing and has to be clarified as to whether epinephrine is to be administered regardless of symptoms. Often the parents understanding also differs from what the doctor has written.	12/2/2016 2:07 PM
28	Always welcome continuing education seminars and presentations on food allergies in schools...	12/2/2016 1:10 PM
29	No	12/2/2016 1:04 PM
30	None.	12/2/2016 12:59 PM
31	Here we do a lot about educating all the students about not sharing food and how others might have allergies and how that affects them. Our students, even the Kindergarten students follow these rules and watch out for each other.	12/2/2016 12:48 PM
32	Physicians/practioners need to have orders signed by the parent in their office before faxing to school. Am constantly hunting down signatures. Also, Physicians making up their own forms which do not have all the needed information on it such as self carry/administer and sign off spot for school nurse.	12/2/2016 12:48 PM
33	Legislators should listen to nurses and not parents. You are making our jobs so much harder. Training laypeople is dangerous business.	12/2/2016 12:42 PM
34	There should be a state law that states number of nurse to student ratio for safety.	12/2/2016 12:31 PM
35	District wide plans do not work because they are focused on the peanut/nut allergies Plenty of children have life threatening allergies to milk eggs soy latex That require individual attention	12/2/2016 12:29 PM
36	Epinephrine is too expensive for families	12/2/2016 11:49 AM
37	I want to move toward what is modeled in the Massachusetts school system. Making schools "Allergy Aware Zones" versus "Peanut Free" schools/tables. Schools that state "Peanut Free" tends to give a false security and may increase liability. Student self-advocacy is key as they mature and prepare for adulthood.	12/2/2016 11:35 AM
38	Would like it if district adopted an non foods celebration policy or only foods purchased from school	12/2/2016 11:31 AM
39	I am seeing an increase of not only "Food Allergies" but also changes in peoples diets overall-food avoidances, gluten free, lactose intolerance....	12/2/2016 11:30 AM
40	Resources in private schools are very limited. These schools should be included in having staff trained in administering epinephrine to students with anaphylaxis. It also would be beneficial for the trained staff members to administer to IDENTIFIED children as well since time is of the essence. Many parents are upset that the epi-pen cannot just be given by the nearest trained adult and if they have a younger child are worried the child would not be able to self-administer if they had a self-carry order. It is silly to wait for the nurse to run down to the cafeteria, classroom, recess area, etc to give a life-saving medication for IDENTIFIED students since in the public schools staff are now being trained to identify anaphylaxis and administer epinephrine to UNidentified students, and staffing a nurse in the cafeteria and/or at recess for identified students is a complete waste of time and money since these incidents are thankfully not everyday occurrences.	12/2/2016 11:05 AM
41	I think the DOE should have made a video to present the power point presentation that they want school nurses to teach staff regarding Epinephrine administration for undiagnosed students.The CPR portion could be done by a certified CPR instructor. The rest of the power point could be viewed at the discretion or flexibility of the volunteer, with any remaining questions to be answered by the school nurse, if any. The powerpoint does not even cover the EpiPen Jr. dosage versus the EpiPen. The expectations of teachers to assess students medically and the nurses to act as certified teachers is going beyond the boundaries of each profession. The fact that someone has to VOLUNTEER makes it very difficult, as it requires additional training/time to teachers that just want to teach and already have many other criteria that they have to follow. The other problem I have with the new EpiPen administration is that it can only be given during the school day and on school grounds. How does that address field trips, sports or other activities? I think the state has exposed themselves to a possible lawsuit because if a child has a severe allergic reaction on a field trip who is undiagnosed and is not given an EpiPen, they are going to ask the state why field trips were not included as well other school related activities.	12/2/2016 11:02 AM
42	no	12/2/2016 10:59 AM
43	no	12/2/2016 10:49 AM
44	Parents of the nut allergy students like our policy. However, other schools in the district do other things that work well. Having a district be nut free is not realistic	12/2/2016 10:41 AM
45	I feel parents should be a little more responsible to provide safe favorite foods for their child. Parents are required to provide medications, so I feel it would be helpful if they provided alternates on days when the free school meals might contain an allergen.	12/2/2016 10:30 AM

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46	The opt-out law needs to be changed. In an emergency situation, how can anyone expect the nurse, or lay person for that matter, to waste precious time looking up who is excluded from receiving life-saving treatment. Whose idea was that anyway to require us to standby and watch helplessly while a child goes into a serious, even fatal decline when we could have saved him or her with Epinephrine?	12/2/2016 10:18 AM
47	Education! Education! Education the MOST important part of this job.	12/2/2016 10:04 AM
48	Lower cost of Epipens	12/2/2016 10:01 AM
49	identified allergy by physician with documentation by physician to allow student not to sit in allergen free areas	12/2/2016 10:01 AM
50	I would like to have all classroom activities including parties celebrate without any food.	12/2/2016 9:58 AM
51	with the obscene increase in cost of the epipen I find it impossible to require that every student with a food allergy has his own epipen. Especially when I have only uses 1 epipen in 20 years as a school nurse which was for a student with a previously undiagnosed allergy. In these 20 years I have thrown away over 300 expired epipens and used only 1. It seems to me that it would make a lot more sense to keep a couple as stock items and not ask each family to supply their own.	12/2/2016 9:28 AM
52	I have seen children with PE's and the MD's do not mark off epi pen or anaphylactic allergies on forms. I point it out to the parent and they are shocked and have the MD re-do forms.	12/2/2016 8:26 AM
53	Need more cooperation from parents and MD in regards to bringing in the epi-pens and sending us complete and accurate orders.	12/1/2016 12:30 PM
54	No.	12/1/2016 10:09 AM
55	None	12/1/2016 8:37 AM
56	I believe school districts should have epi-pens in all their schools. It is a waste money to have all these unused epi-pens in school while the parents then need to have another set at home. There should be a legislative way that a parent would resupply the school epipen stock if the school uses its epipen on a student.	11/30/2016 9:08 AM
57	I feel it is important that all districts in CT follow the same safety steps like in the field trip case-see above-to ensure the safety of the students. I have discussed this with the Department of Education attorneys and they helped make the above plan.	11/29/2016 12:08 PM
58	Keep kids safe.	11/29/2016 11:41 AM
59	No	11/29/2016 11:02 AM
60	Too many activities that involves food: birthdays and holiday parties	11/29/2016 9:57 AM
61	Should students be periodically tested or professionally challenged under MD care, to see if allergy has lessened in severity?	11/29/2016 9:49 AM
62	We always have a nurse available and so do not have trained non nursing personnel	11/29/2016 9:08 AM
63	n/a	11/28/2016 1:05 PM
64	NONE	11/28/2016 11:09 AM
65	there should be a special med auth form and emergency plan combined that the parent gets from the prescriber's office	11/28/2016 9:57 AM
66	No	11/25/2016 8:59 PM
67	Just above # 16 is a nightmare	11/23/2016 8:17 AM
68	no	11/22/2016 9:10 AM
69	no	11/21/2016 10:14 AM
70	WOULD LIKE TO IMPLEMENT A DISTRICT WIDE POLICY OF NO OUTSIDE FOOD TO INCREASE SAFETY OF THE STUDENTS.	11/21/2016 9:09 AM
71	no	11/18/2016 3:39 PM
72	No	11/18/2016 1:33 PM
73	none	11/18/2016 1:29 PM
74	none	11/18/2016 1:25 PM
75	Time spent with preparation & training help to prevent exposure & anaphylaxis of known allergies in school.	11/18/2016 11:11 AM
76	NO	11/18/2016 10:10 AM

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77	no	11/18/2016 7:59 AM
78	The expense of medication is out of sight. They expire in a year and it is a hardship for families.	11/18/2016 7:27 AM
79	no	11/17/2016 3:37 PM
80	I wish all schools were nut free	11/17/2016 1:55 PM
81	NA	11/17/2016 12:33 PM
82	I had no problem getting 8 adult and 8 jr. Epi-pens from the Mylan company this summer. It is an involved process and took about 2 months, so nurses should start in about May for the next year.	11/17/2016 11:59 AM
83	More students are getting exposure treatment this school year at the allergist.	11/17/2016 11:43 AM
84	No	11/17/2016 11:27 AM
85	MD need 1 plan thorough the state to use. AND MDs NEED TO USE THEM. INCLUDING picture on how to give. AND if a md gives a parent an order that office should teach them the realities of reading labels, and how to use the EPI, and how to call 911.	11/17/2016 10:41 AM
86	I would love to see more schools in CT become peanut free. We are taking on too much liability by relying on parents to comply with our requests. I find that if it does not directly affect their child they don't bother.	11/17/2016 9:41 AM
87	OPT out Epi-pen administration form is very confusing to parents , should be done away with.	11/17/2016 9:35 AM
88	At the elementary level, I would like to see schools be able to have 2 sets of stock Epi and Epi Jr. that can be used in the event of a reaction. Parents must resupply the school if the med is used on their child with a known allergy. Every year I dispose of thousands of dollars in expired Epi-pens.	11/17/2016 9:21 AM
89	lack of sub nurses can put students at risk.	11/17/2016 9:14 AM
90	Have all the health care providers on the same page for treatment for life threatening allergies, and use and provide to the school nurse an action plan that is consistent with best evidence practice.	11/17/2016 9:08 AM
91	no	11/17/2016 8:59 AM

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PUBLIC COMMENT

Tonya Winders President and CEO Allergy & Asthma Network

Education Committee
Room 310, Legislative Office Building
Hartford, CT 06106

RE: Substitute House Bill No. 5521, Public Act No. 14-176, An Act Concerning the Storage and Administration of Epinephrine at Public Schools

To whom it may concern,

Allergy & Asthma Network (“Network”) is the nation’s leading nonprofit dedicated to ending needless death and suffering due to asthma, allergies and related conditions through outreach, education, advocacy and research. The Network works closely with states and state school nursing organizations to promote appropriate, safe and effective care for students in a school setting

Connecticut has long been a leader in school health, however the Network has concerns regarding Substitute House Bill No. 5521, Public Act No. 14-176, *An Act Concerning the Storage and Administration of Epinephrine at Public Schools*.

- The “opt-out” option in the 2014 stock epinephrine bill creates some legal and ethical issues for school nurses. While parental control is important, it is not reasonable to ask a nurse or any school personnel trained to give available epinephrine to not administer this life-saving drug and watch as a student dies.
- State Department of Education guidance should be updated to reflect current evidence-based practice, including:
 - o Not serving peanut, tree nut, and shellfish products in cafeteria – which also promotes lunch-time inclusion for food allergic students who can then sit with any of their peers who get lunch at school
 - o Not using food for celebrations or rewards
 - o Evaluating students with food allergies for 504 plans
 - o Promoting emergency allergy plans that specify epinephrine as the first-line medication rather than antihistamine (i.e., Benadryl). Current guidance from the leaders in the field support “epinephrine first and epinephrine fast” as the first line and ONLY treatment for anaphylaxis, a life-threatening allergic reaction.
- We believe that every student should have access to a qualified school nurse every day. There is no shortage of school nurses, just a shortage of funded school nursing positions. School nurses bring the skills of care coordination, leadership, quality improvement and community and public health nursing to our most vulnerable population - our children. o Eight percent of all children have a food allergy, with almost 40% having a history of a severe reaction (Gupta, et al., 2011). The prevalence of food allergy among children under the age of 18 increased 18% percent from 1997 to 2007 (Branum & Lukacs, 2008).

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- Peanut allergy doubled in children from 1997-2002 (Sicherer et al, 2003). Fatal food anaphylaxis is most often caused by peanuts (50-62%) and tree nuts (15-30%) (Keet & Wood, 2007).
- In a survey of school epinephrine administration, approximately 25% of had no previous food allergy diagnosis. (McIntyre, Sheetz, Carroll, & Young, 2005).

The unintended consequences of the Connecticut guidelines are too great as the matter of life and death is weighed. School nurses bring assessment skills to our children where they spend most of their day and can provide preventative and direct care to allow them to fully access their educational program and lead healthy and productive lives.

Thank you for your consideration of these comments.

Sincerely,

Tonya Winders
President and CEO

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Amanda Cuevas, Parent

I am writing to express support and gratitude to the individuals who are working to make our public schools safer for children with food allergies. I am also writing to add my voice to those expressing concern about current practice in school food allergy management.

In the interest of keeping this as brief as possible I want to state that I agree 100% with the comment submitted by Gina Menett Lee. That well thought out comment accurately reflects my concerns as a parent of a child with food allergies. I support the outlined measures of inclusion, prevention, and management as well.

A few real life examples from SmallTown, CT:

1. My daughter rides a bus to school where the only safety precaution is "No Eating Allowed on the Bus." This week while riding the bus, my daughter found a pistachio shell on the bus floor. There was an incident last year of someone eating peanut butter on the bus. I also recently discovered that bus drivers are unaware of which children have known food allergies unless notified personally by parents. If a food allergy reaction occurs on the bus the bus driver can only pull over and call 911. Lives are lost by delayed Epinephrine administration.
2. During a grade-wide Thanksgiving Feast the only reason pumpkin bread (homemade by parent volunteers) containing walnuts was not handed out to all students at random was because I had declared myself in charge of all bread handling and serving and had inspected each loaf, throwing away the nut-containing loafs. I had previously been reassured by staff that

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all parents knew not to send in bread containing nuts. I personally know of 5 students' lives who were put in danger by this celebratory event and those are only the students' whose nut allergies I'm aware of.

3. My daughter was in a "Nut-Free Classroom" for Kindergarten. However, the children eat snack in the classroom and 4 & 5 year old children are responsible for going into their lunch boxes and determining what item was sent in as their classroom snack. The only day I was present during snack time I noticed that the child sitting next to my daughter was eating peanut butter crackers. I assume his parents meant those to be a part of his lunch and not his nut-free classroom snack. My daughter was not necessarily put at risk by this because she has been desensitized to peanuts. However, I include it as an example of the fragility of a "Nut-Free Classroom" approach.

4. After my daughter gleefully left the segregated "Nut-Free Table" in the lunchroom due to successful peanut desensitization, only one student was left sitting at the table. The district's policy, as it was described to me, was that students who bought school lunches would be allowed to sit at the Nut-Free Table because the school's lunches were always nut-free. Unfortunately, this is a hard distinction for Kindergartners to make and as a result most kids would avoid that table when eating school lunch because they had to avoid it on days eating bagged lunch. On two separate occasions I observed a student sitting completely alone at the table in an otherwise crowded lunchroom. I was rarely in the cafeteria so I assume this likely happened more than twice. When I mentioned it to the lunch staff they told me that it was "because he has nut-allergies." After I explained their own policy to them they recruited other Kindergartners to switch tables. Kindergartners are typically sweet little human beings who want nothing more than to be helpful and a good friend to classmates so recruitment was easy. I would have loved to see the adults have the same initial level of compassion as the children did once they were informed of the problem.

Thank you,
Amanda Cuevas

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Angela Nadeau, Parent

I am writing you because I want to join the fight to allow the administration of Epinephrine on school buses. I am the mother of a boy who attends Kindergarten in West Hartford. He happens to have a peanut allergy and the morning bus ride just happens to be one of the highlights of his day.

Prior to the start of school I was most worried about how he would fit in with his new school, classmates and teacher, and whether other children would be sitting at the peanut-free table with him. I never imagined the jeopardy his life might be in until approximately one week prior to the start of school. That is when I found out that my son's bus driver would not be EpiPen trained nor be able to administer Epinephrine on the bus. I am the daughter of an EpiPen-

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trained bus driver in Massachusetts and perhaps that is why the thought never crossed my mind about my own son not having these measures in place.

He is too young to self-carry or self-administer his own EpiPen. He relies on us parents to read labels and carry the EpiPen at all times to save him from a life-threatening reaction to peanuts or tree nuts. We have seen his anaphylactic reaction before; approximately one hour after eating even traces of nuts, his tongue, lips and throat swell to the point of incomprehensible speech. He is on the school bus approximately one hour after breakfast. While we as parents do our best to read labels to ensure our son is reaction free, there are no guarantees. There is the risk of cross contamination and the risk of other children having peanut residue on their hands or eating on the bus without the driver knowing. This bill being passed means that my son will have a chance at life if he were to have a reaction on the bus. Currently, the protocol, per the transportation department, is to have the driver pull over and radio dispatch. Dispatch will then call 911 and emergency services are then sent to the location. This takes critical time that my son will likely not have. Having already experienced needing to call for an ambulance to our house, we know it can take approximately 10 mins for an ambulance to arrive to our home with a direct 911 call from our house.

We are fortunate that our school is so accommodating to my son's peanut allergy. I have been told that the bus is "an extension of the school day." If this is so why would processes not be in place to deal with an allergic reaction on the bus vs. in the school? I placed calls to the transportation department and the school. Several calls later, I was told that best option for my son would be to ride a mini bus that had room on it for him and came near our neighborhood.

They could not tell me what time it would be coming, how long the ride would be, or how many other students would be on it. My husband and I thought carefully and ultimately decided against this option for many reasons. My son had watched for years as the other children in the neighborhood gathered together at the bus stop and he had been told that he was finally going to get to ride the bus with those other children in the neighborhood. He was ecstatic about this and looking forward to the start of kindergarten. With this new bus we could not be sure what the needs of the other children would be and how that may impact our son. I even requested the opinion of my mother who has EpiPen training as well as experience driving special needs children.

We chose to research the route of the current bus he was scheduled to take and make a careful decision to keep him on this bus due to the short duration (approximately 20 mins) and wanting him to feel included with the other neighborhood children. He gets to sit with his best friend in the neighborhood and he loves it. I live everyday with anxiety of if he will get to school without having a reaction. My choices are to hope he gets to school reaction-free or to pack up my 2 year old and either follow the bus to school or drive him myself. Neither option is favorable to me as a full-time working mother.

I hope I can help educate others on the importance of having this bill passed so that children with allergies such as my son can have a safer ride to school without being segregated with

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other children who truly need a bus monitor. This simple training and willingness of a trained adult to administer Epinephrine is life-saving, and what can be wrong with that?

Sincerely,

A concerned parent

--

Christina Ilardi, Parent

To whom it may concern,

I am thrilled that the issue of food allergy management in Ct schools is being investigated and addressed, so thank you for your work on this matter. It is an area in need of vast improvement. I will speak a bit about my personal experiences in fighting for my children's safety and inclusion in their public schools, and the frustration of the battles coupled with settling for inadequate solutions that compromise these basic principles. As a nurse myself I have immense frustration with the onus on parents in many cases to both explain, decipher, request, and sometimes implore school districts to follow medical best practice. To say nothing of the financial expenses incurred and time spent in the process, for many.

I have three children, two of whom have multiple complex medical issues. Food allergies are but a small part of our medical picture. Part of their other diagnoses include medically prescribed very restrictive diets, as their esophagi are inflamed and narrowed. Food elimination has been a very difficult thing for both of them as you can imagine. However, nothing prepared us for the difficulties we would face in their school. Our challenges have been multi-faceted, but food issues have been significant. I have found that despite good intentions and many compassionate staff members, there is an egregious lack of understanding and implementation of food allergy protocol, CDC guidelines, and inclusion definitions. In our school district, we've continually dealt with a "plan as we want, deal with special needs later" attitude. Repeatedly, we've been forced to figure out for ourselves how best to "partially" include our daughter, particularly on field trips. A stunningly high percentage of field trips in our district include gratuitous food offerings, some as treat/reward – despite the steadily increasing number of students each year who cannot participate due to medical restrictions including food allergies – and despite a written district regulation stating that curriculum/school day activities will be food-free if all cannot partake. Year after year, situation after situation, we educate and contest multiple trips, events, fundraisers, parties etc – that exclude our children by their very nature. We attempt to do this in good spirit. We are well versed in the law, but feel that many school staff are not; we also feel that there is a discord between general perception of "allergies"- and their necessary protocol to minimize risk – and the data-derived national guidelines that outline quite nicely, best general practice. We feel that there is somewhat of a "backlash" surrounding the issue of food allergies in schools, and too much discretion is given to districts to implement risk reduction strategies. It's outlined by the CDC – why not standardize school district protocol in some way and require policies stating so? Individual plans can and would still be tailored and expand upon generalized protocol, but given the sheer number (growing exponentially) of food-

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restricted students and the potential consequences of poor/absent risk reduction strategies, standardized district policies based on national guidelines seem like a good idea. Community “pushback” related to strategies to keep students safe should have no bearing on their implementation, but yet it seems that public misconceptions, misinformation and sentiment surrounding food allergies guide and inform many school decisions. Why are we allowing a different handling of food allergies in our schools vs other special needs and student safety issues?

It is imperative that school nurses, administrators, and 504 personnel receive more comprehensive training on the issue of food allergies and special needs inclusion. Empower school staff with the knowledge they need about their students to best include them and keep them safe. Empower them with medical facts, best practice guidelines, and basic SPED training to understand inclusion models. Time and money are ultimately saved when plans are made proactively and smartly, averting both safety issues and contention with parents. Summarily, no family or parent should be forced to fight these battles for basic safety and inclusion of their children in public schools. The state of Ct has the opportunity with this task force to examine carefully where and how to improve the lives of many children and families. The data needs to be interpreted with an understanding of the full scope of impact of food allergies or restricted diets on these affected children and families. One can easily measure anaphylaxis rates and costs associated with certain issues; it is harder but imperative to try to grasp and qualify and quantify the abstract sequelae of food-related special needs. The psychosocial costs of exclusion are immeasurable. The stress on already-stressed parents is incalculable. The close-calls with safety are inestimable. The lens with which this issue is viewed by the CT task force needs to be wide, and I implore you to really see the gaping holes in food allergy management in CT schools - and close them. Our children’s lives depend on it.

Thank you for your time,

Christina Ilardi

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Debra Denhart, Food Allergy Advocate

Dear Food Allergy Task Force Members,

I am very excited to see some action being taken regarding, the investigation of schools and their treatment of children with food allergies. As the mother of a child with multiple life threatening food allergies, I have been battling with the public school system for over 10 years. My oldest daughter, Carlese, had been in the Wallingford Public School System from the age of 4 years old, as a kindergarten student to the age of 14, as a freshman. Carlese, now 16 years old, has life-threatening food allergies to goat’s milk, cow’s milk, eggs, peanuts, hazelnuts, almonds, beef, peas, sesame, mustard, lentils and avoids all tree nuts and some spices. She was diagnosed with multiple life-threatening food allergies at the age of 10 months old. This testing was done initially in Denver, Colorado, our home at the time, after a severe allergic reaction to

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scrambled eggs. Carlese has a contact, inhalation and ingestion reaction to her life threatening food allergens.

As the parent of a child with life-threatening food allergies, I have been threatened and bullied by the school administrators on many occasions. It is also concerning to me as a parent, the repeated negligence the Wallingford School District has displayed in their treatment of Carlese and her multiple life-threatening food allergies over our 10 years in the district. The Wallingford School System's negligence has put Carlese's life at risk on multiple occasions. I will be addressing some of these negligent acts. While at Dag Middle School in Wallingford, on a field trip, the leader of the trip allowed students to carry ice cream onto all of the field trip buses. I was a chaperone on the field trip and kept my daughter close to me, as hundreds of kids loaded onto to the buses with various milk products. Not only would the buses now be contaminated with the allergens on three buses which would be transporting other students at the end of the day, but Carlese was at risk by just sitting on the bus with students and their milk products all around her.

I strongly feel that whether it's a field trip or any school event utilizing the buses which will be transporting children at a later time, there should not be any food allowed on any buses transporting students. Food on the buses can put a child, like my daughter at risk for an allergic reaction. It has been a constant battle for me as a parent to make sure that no food is consumed on the buses which Carlese will be traveling in.

On another field trip at Dag Middle School, I pleaded with the nurse of the school district, asking that ice cream not be eaten on the Lyman Hall field trip due to Carlese's life-threatening food allergies. The nurse for the district said, they would not change the trip which has been a tradition. I then asked that the students wash or wipe their hands after eating any milk products. She continued to state that, it was not possible to do that.

After this response, I contacted the Superintendent of the Wallingford School District and he said, he would support the District nurse's decision and there would not be any modifications to the field trip. Carlese did have an allergic reaction from another student who brushed up against her with her ice cream while on the field trip, despite my pleas to modify the trip due to Carlese's multiple life-threatening food allergies.

In another incident at Dag Middle School, a teacher brought in cupcakes with unsafe ingredients for a food celebration for her class. When Carlese arrived in her classroom, remnants of the food were everywhere on the floor and on her desk. I addressed this issue in one of many 504 Accommodation Plan meetings and the district nurse stated that, Carlese could use wipes on any areas which she felt could be covered with allergens. This type of statement from the district nurse regarding allergens, suggests to me that food allergy education needs to be done.

My recommendation is that there should not be any food allowed in the classroom due to food allergies. Food in the classroom puts each child at risk, like my daughter to touch a desk that has been contaminated with allergens.

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We did change schools due to Carlese being bullied from other students while at Dag Middle School. We switched Middle Schools and she began at the Moran Middle School in 8th grade, still in the Wallingford School District. While at Moran, there was again, negligence displayed. I emailed the assistant principal regarding Carlese's food allergies and my concern that there may be food in her classroom. I was told in the emails that the teacher was very aware of Carlese's food allergies and there would not be any unsafe/allergen type of foods in her class. However, her science teacher did bring chocolate and cheese type of foods into the classroom for the students on two different occasions. This resulted in two 911 calls and hours in the Yale emergency room, while Carlese was in school, as she had two anaphylactic reactions from these negligent actions spaced months apart, by the same teacher.

Regarding past experiences with food in school, I feel the only place food should be eaten is in the cafeteria. Children walking around with Starbucks coffee or foods containing allergens while walking in the hallways, is also a risk factor for not only my daughter, but other children with food allergies. Hallways can be tight, especially in high school and kids are carrying various drinks in the hallway which can be easily spilled on Carlese. If this were to occur, it could cause her to have an allergic reaction. Not to mention the fear this can evoke, knowing that at any moment, that drink could end up on you and put your life at risk.

While in the Wallingford Public School District, not only was my daughter bullied by other students and staff, but I was bullied by the administrative staff in my efforts to keep Carlese safe. The 504 Accommodation Plan meetings were not routinely productive. But more of an opportunity for the administrative staff to demonstrate their power. I hope that some changes are made and that no one has to endure the struggle and negligence we endured while attending this school district for 10 years.

Fortunately, we have moved and are currently in the Cheshire Public School District. Although there have been some challenges, my requests for change have been received well and the support of the school district is wonderful overall. The school district cares about Carlese and her safety as well as supports her inclusion. Inclusion is key to children with food allergies. We did face a challenge regarding segregation on one occasion. While attending a class which was changed to the cafeteria, Carlese was pulled out and taken to the library, where she was told to sit in the far back corner by herself until the class was over. The regular teacher was not in that day, so she was put in the library. Isolation and segregation were used due to her food allergies. The staff didn't want her around the other kids in the cafeteria for study hall because they would be eating. This was very upsetting for Carlese, as you can imagine. It was like she had a disease or something. This type of food allergy management is not acceptable and can be traumatizing, both emotionally and socially to a child with food allergies.

I did address this issue with the vice principal at the time, and asked that her 504 Plan state, Carlese will not be excluded from her class. If her class is in the cafeteria, then she would also be in the cafeteria and the proper supervision would take place. Inclusion is the answer, not exclusion when it comes to children with food allergies. This was added with full support to her 504 Accommodation Plan.

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There was also an issue concerning the cleaning of the cafeteria tables which has come up recently. The cafeteria staff was cleaning the tables with buckets of water and a rag. When it comes to removing the allergens from tables, a bucket of water was used to clean ten other table. I voiced my concern that this is not a safe cleaning method when it comes to cleaning Carlese's tables, due to cross-contamination. A spray bottle with the proper cleaning solution and a clean cloth should be used on any tables in which children with food allergies will be sitting or eating at. After addressing my concerns of cross-contamination when the cafeteria tables are cleaned, the staff ordered spray bottles for cleaning and the proper cleaning method for the allergy tables has been addressed.

In conclusion, I have consolidated recommendations in the list below, through my many years of struggle and experience of negligence in the public school system. It is my hope that some change will take place and schools will be a safer place for children with food allergies. Food should not be allowed in the classroom. If food is brought in, the students or teachers should dispose of it and wash or wipe their hands. Staff should not eat at their desk due to the risk of cross-contamination.

The proper cleaning of cafeteria tables with a spray bottle and a clean cloth or wipes should be used to clean any tables, which children with food allergies will be sitting. A bucket of water and a dirty rag should not be used due to the risk of cross-contamination.

Inclusion of children with food allergies should be the practice, not isolation and exclusion. Food should not be allowed on school buses.

Bus drivers should be trained on all buses on the signs of an allergic reaction and the administration of an Epi-pen.

Food should only be allowed in the cafeteria during breakfast and lunch during school hours. Drinks and food should not be allowed by students in the hallways. When there is school events, food should not be involved as well. Keeping food out of the public school events can help keep children with food allergies safe. There should always be a trained medical professional in the school building during the same hours that the students are in school.

I hope my experiences and recommendations will help in educating others when it comes to children with food allergies. Having a safe school environment without negligence and isolation is critical for my daughter and other children with food allergies. By putting laws in place to protect children with life threatening food allergies, you have the power to save the life of my daughter, Carlese, and many other children just like Carlese who struggle with food allergies every day.

Thank you

Debra Denhart
Food Allergy Advocate
Unites States Air Force Veteran

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Concerned mom of CT public school student

Dear members of CT food allergy task force,

I would like to remain anonymous for the fear of retaliation from some of my child's 504 team members/my school/district. My son is in middle school and has 504 for food (peanuts/tree nuts/coconut) allergy and asthma. He had IHCP for this from k-1st month of 5 th grade. Then we got 504 due to non-cooperative and refusing to understand class teacher and other multiple new school staff/administrator. After putting lot of effort into educating various levels of school staff and educating myself in my child's right of safety and equal inclusion (concept not clearly understood by school staff) compared to non-disabled peers, we finally had a 504 plan with acceptable clear wording without leaving much room for loopholes. This year new 504 coordinator removed key safety and "equal inclusion" wording even after agreeing to retain all wording of last school year's 504 plan at audio recorded 504 meeting. 504 meeting were on 9/19/16; we got the draft to review after 3 weeks from the meeting after I followed up. Apparently they are not responsible for typing up the plan with agreed wording at the meeting or within 2-3 days after meeting.

We reviewed the plan and send detail email with our questions/concern and asked them to provide us in writing why they dropped certain key wording. Apparently 504 coordinator is too busy with her other work and she said she will work on it when she is free next...no concrete 2-3days. This is clear stalling and harassment practice by 504 coordinator because apparently there is no law or state requirements governing these kind of things. We asked twice by email that while we are waiting for them to get back to us with answers to our questions and concern on new 504 draft, is our old good 504 plan still in effect. No one from the team has bothered to answer it. 504 coordinator said she left office early on Thursday 10/27 due to sickness and will get back to us upon her return. Why couldn't she answer simple question with "yes, old plan is in effect till new plan is finalized" or "no"! Apparently there is no back up for this 504 coordinator or other 504 team members copied on the email who can answer our emailed questions or concerns or resolve anything.

We are treated so poorly by our 504 coordinator and she seems to have support of all her higher ups. They included us parents in the 504 meeting but lied to us on audio recorded meeting and deceived us by removing very important wordings/language on last year's 504 plan even without discussion and agreement at our 504 meeting. They don't want to provide "equal" inclusion. They won't even define inclusion for us. Last year my child's 7th grade had end of the year team celebration with Dublin donuts doughnuts. I told them they are not safe for nut allergic child like my child to eat, and to consider either replacing it with safe Oreo or chocolate chip cookies or cupcakes or consider nonfood activity for team wide celebration as there is nothing life essential about DD doughnuts. They said they will not change their plan and I should send some safe food for my child to eat, that's their concept of equal inclusion compared to non-disabled peers! They said fine we will buy safe pretzel and he can eat pretzel. I said, that's not same as sweet treat. They said every child in 7th grade team will have a choice

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of DD doughnuts or pretzel. I explained them that they are truly not providing my food allergy disabled son equal choice, infant he does not have choice. But I don't think team leader or school nurse understand equal inclusion to even enforce it.

I can go on and on about difficulties and resistance we face about safety and equal inclusion at our public school located in Connecticut in Fairfield County. Every year it's new 504 team and we start at ground zero. It's exhausting and takes great toll of our mental and physical health. Please create guidelines that are not mandatory but every public school not only elementary but also middle and high school 504 team must follow.

Thank you for all your time and effort you are putting in this task force.

Thanks,

Concerned mom of CT public school student

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Mom from Fairfield, CT

Hello,

I have a daughter in public school in Fairfield, CT. My daughter has life threatening allergies to peanuts and tree nuts. The school has done a good job at keeping her safe but there are many areas that need improvement. The areas I would like to see improved are cafeteria management, after school programs and bus accessibility.

For the cafeteria, we have 2 nut free tables. However, this is isolating for the allergic children and forces them to sit in a corner, away from their friends. I would like there to be the opposite, a NUT table. Lots of school districts are doing this. The children that bring in nut products in their lunch, by choice, may sit at this table. Management and cleaning will be MUCH easier in this model. Our allergic kids have no choices. They are forced to sit away from the group. The other kids can eat and sit wherever they want. Please consider this model for state wide cafeteria management. There are districts in CT doing this very successfully. Currently, there is no system in place for my daughter to attend after school programs and have her epi pen with her. I would like all after school providers to be trained and required to administer epi pen as needed. I understand it's not a "school" function. But these activities are offered by and held at the school, so there should be some cross training involved. My daughter is now excluded from these activities she wants to do because she won't be able to have her epi pen with her.

Finally, my daughter is currently unable to ride the bus because there is no assistance for her on the bus. I am requesting training and availability for epi pen trained personnel to be on the bus. I understand this is a financial concern, however, this can be a volunteer job, and perhaps a school employee can be designated to take the short bus ride with those that need monitoring. I understand this is a complicated proposition, but I do think it needs to be addressed. It's

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completely unfair and unjust for my daughter to be excluded from the bus because she can't have her life saving medication with her.

Thank you so much for addressing these concerns. We are eternally grateful for any and all assistance we can get from the task force.

Mom from Fairfield, CT

--

Gina Mennett Lee, M.Ed., Owner, Mennett Lee, LLC

Background

I have been asked to submit public comment as an expert in the management of food allergies in the school setting. I hold Bachelor's degrees in both Elementary Education and Special Education, and a Master's degree in Educational Leadership. In my public school career, I taught elementary school and middle school as a special education and regular education teacher. I also completed an internship as a K-8 principal. In 2007, my younger daughter had a near-fatal reaction to a food she had eaten many times without incident. When I returned from the hospital, one of my first thoughts was that if her reaction had taken place in my classroom, I would've lost her. The food allergy management practices at that time would have resulted in a delay in her receiving the medication that had saved her life.

Shortly after this incident, I started a small support group. As it grew and our mission was defined, we expanded to serving the greater community. In 2011, that support group became Food Allergy Education Network, a CT-based non-profit for which I served as President until 2014. During this same period, I led a small group of parents to advocate for a policy change in our school district. After 4 years of advocacy, a committee was finally formed to strengthen policy in our district and I was asked by the BOE Chairman to co-chair that committee. The policies and practices that were adopted by our town that made the biggest impact were: greater identification of children qualifying for 504 plans, epinephrine auto-injector and general food allergy training of all staff, bus driver training, eliminating the use of food for rewards, parties and celebrations, and reduction or elimination of unnecessary food in the curriculum.

In 2014, I began my role as a Food Allergy Consultant and Educator specializing in food allergies in the school setting. When I view the challenges faced in regard to managing food allergies in schools, I view them from many perspectives: as a parent, an educator, an administrator, a teacher, and an advocate. I use this knowledge to help schools develop effective policy, to help parents navigate the school system and to advocate for the inclusion and safety of children with food allergy.

I speak at workshops, conferences, and webinars across the country and internationally. I have written for Allergic Living Magazine, created resources for Kids with Food Allergies (a division of Asthma and Allergy Foundation of America), created resources for Allergy Home, provided an international webinar for Food Allergy Research and Education, co-authored the Preschool

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Food Allergy Handbook and also provided expert written testimony in a landmark food allergy case in another state.

In the state of Connecticut, I have worked with preschools, teachers, school nurses, administrators, parents, PTAs, food service providers and others. The following public comment is based on all of above experiences.

In discussing food allergy management in any setting, there are three tenets that must be in place at all times and should inform all other actions.

1. The child must have rapid access to epinephrine at all times
2. The child must be supervised by someone trained to recognize the signs and symptoms of anaphylaxis as well as trained and willing to administer the epinephrine
3. The child must avoid his allergens.

Food Allergy Policy/Practice:

When my own daughter was first diagnosed, 1 in 25 children had food allergies; that number is now 1 in 13. Schools are seeing children not only with allergies to the top 8 foods (milk, soy, egg, wheat, fish, shellfish, peanut and tree nuts) but also a host of other foods. The initial management techniques that were put in place when allergies were less common and peanut was often the sole allergy, now require additional thought and revision.

Connecticut has done many things well. Our state was one of the first to create food allergy guidelines, our schools have access to stock epinephrine and have school nurses on staff. These are measures that other states may not have. However, it is time to revisit the issue of food allergy management. In many schools, the guidelines were adopted in the form of a one-page policy and not much else. Because of the enormous amount of responsibilities put upon schools in this day and age, food allergy management is often a lower priority than perhaps school safety and budget concerns.

So what one finds now are wide discrepancies in how food allergies are managed district-to-district, school-to-school, and even classroom-to-classroom.

I often get requests from parents asking what school districts would be good for them to move to. Because the management piece so greatly impacts the child's experience as a learner and a person as well as the quality of life for the whole family, people are willing to move to find a safe and welcoming environment.

This means to me that there is much more needed on the state level to ensure the safety and inclusion of children with food allergy. It is unacceptable for families to have to move in order to receive accommodations that are necessary and are legally required. When advocating for accommodations for their child, some families also find themselves at odds with the very institution that they should be able to turn to for support. As a former teacher, this saddens me. Parents should know that their child will be both safe and included in their chosen school no matter where they are in the state and our classrooms should be a safe haven for our children. Furthermore, parents are often unable to find information about how individual towns care for children with food allergies. So there are issues with both consistency and transparency.

How do we address issues of consistency and transparency?

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There needs to be consistent education, training and implementation of best practices. This can be achieved by setting minimum standards for all schools.

In 2014 the CDC released Voluntary Guidelines for Managing Food Allergies in Schools and Early Care and Education Programs. These guidelines serve as a road map that all schools should be using when developing food allergy policy and regulations, as they reflect current research and best practices. What we know and understand about food allergy is rapidly evolving, thus much has changed since the CT guidelines were first developed. Going forward, any policy, legislation or regulations developed should account for the evolving nature of food allergies and should be written to reflect the need for updating on a regular basis.

The CDC recommends that all schools develop a Food Allergy Management and Prevention Plan (FAMPP). It would be wise for CT to update its guidelines to match the CDC guidelines, or to outright adopt the CDC guidelines. The CDC states the following as priorities when developing a FAMPP.

1. Ensure the daily management of food allergies for INDIVIDUAL children.
2. Prepare for food allergy emergencies.
3. Train staff in how to manage food allergies and how to respond to allergic reaction.
4. Educate children and family member about food allergy.
5. Create and maintain a healthy and safe educational environment.

If all schools were required to develop a Food Allergy Management and Prevention Plan in alignment with the CDC guidelines, this would go a long way in addressing issues of consistent food allergy practices across the state. However, no guidelines are effective if they are not implemented. It would be helpful to require all school districts to create and make public (publish on websites) a Food Allergy Management and Prevention Plan (FAMPP) that includes both policy and best practice for each of the priorities established by the CDC. This helps with the issue of transparency.

What are best practices?

The CDC outlines in great depth what are considered to be best practices. Some of the practices that I have found to be most impactful are:

- Develop individual written plans for all children with food allergy (504 plans or Health Care Plans, as appropriate)
- Use of non-food rewards, birthdays and celebrations
- Hand washing of all children, staff, and volunteers before/after handling or consuming food
- Strategies to prevent cross-contact
- Training of all staff
- Quick access to epinephrine in all settings
- Prevention of bullying and social isolation
- Create an environment that is “as safe as possible from exposure to food allergens”
- Allergen-free classrooms
- NO Food sharing
- Modeling inclusion

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Below, I will comment on each portion of the task force's agenda.

1) the efficacy of the implementation, dissemination and enforcement of the guidelines for the management of students with life-threatening food allergies and glycogen storage disease, developed by the Department of Education pursuant to section 10-212c of the general statutes, As stated above, there is a lack of consistency across the state. At times, a school may have excellent practices in place only to have a change in administration result in significant gains in effective food allergy practice being lost. This illustrates the importance of written policy and practices as well as individual written plans for each child (504 or other). Commitment from the highest levels of the school administration (Superintendent, Board of Education, Principals) to maintain and adhere to adopted practices is imperative.

(2) methods used by school districts to ensure the safety of students with life-threatening food allergies while such students are being transported to and from school, Again, here exists a lack of consistency. All children with food allergies must be supervised by a trained adult at all times. This "trained adult" may be the bus driver or a trained aid/bus monitor. Many districts, as well as other states, have chosen to have the bus driver trained as it is most cost effective. Bus drivers currently are responsible for the safety of children with food allergies on their buses, and most often without training. I would prefer to have that responsibility with the knowledge of how to respond rather than to be left responding to an emergency without the necessary knowledge to help the child.

The current practice by some bus companies of pulling to the side of the road and calling 911 is unacceptable to me as a parent that has witnessed and responded to anaphylaxis first-hand. Anaphylaxis is considered a medical emergency and immediate action must be taken in order to avoid death. Even a delay in the administration of epinephrine can have dire consequences. What is often overlooked, and warrants mentioning, is that fact that anaphylaxis in the "real world" for lack of a better phrase, happens a lot differently from a medical setting. When an allergist observes anaphylaxis, it is often in a very controlled environment when the medical staff is specifically looking for signs and symptoms of a reaction and monitoring their patient. What is different in a school setting (such as the bus) or even in a home, is that the initial symptoms are often mistaken for another illness or not immediately observed or communicated. It isn't until upon later reflection that one realizes that the initial symptoms were present. The undeniable fact is that the moment one realizes they are experiencing or observing anaphylaxis, is the moment one must react. (Not minutes, not even seconds later.) Research reveals that the earlier epinephrine is administered, the better the outcome.

Furthermore, epinephrine auto-injectors are developed with lay people in mind. They are intended to be administered by people without medical training.

Additionally it is important to understand that 25% of reactions requiring epinephrine in the school setting occur in people without a prior history of anaphylaxis. Given this, there may be incidences in which a child without a known history of food allergy may have a reaction on a bus.

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(3) the plans for the management of students with life-threatening food allergies and glycogen storage disease, implemented by local and regional boards of education pursuant to section 10-212c of the general statutes, to ensure the safety of students with life-threatening food allergies and their inclusion as fully participating members in the school community, This issue of inclusion is too often overlooked. Often safety trumps inclusion when both need to be reflected upon and considered when developing policy and individual plans for students. This issue often crops up when food is used in the classroom. I would challenge educators to really reflect on the necessity of food in the classroom. As a former teacher, I can state that food is usually unnecessary and often a distraction from learning.

When a child is not able to participate or is relegated to another area to eat a different, albeit safe food, we are modeling exclusion. This has implications in school and outside of school. Our children look to adults for guidance on how to act towards one another. If children are excluded in the classroom, this can carry over to birthday parties, soccer fields and the like.

At times, it may be necessary to have food in the classroom. Some examples include cooking class and snack-time. In these instances, the classroom should remain allergen-free. Why should a classroom be allergen-free when so many spaces such as the cafeteria or the corner grocery store are not? Why is this so critical in the classroom?

1. Children don't have the freedom to leave their classroom if they feel unsafe or if allergens are spreading. There have been many times that I have gracefully exited a party or gathering with my daughter because her allergens had become a problem and the hosts were none the wiser. This is because I was thankful my daughter was able to be a part of the event for the period of time that she was able and I didn't want to hurt the host's feelings. In a classroom, the child does not have this option. They remain there all day, day in and day out, sharing classroom materials and working together in groups.

2. For children with food allergies, allergens in the classroom are an unnecessary distraction at best and a danger at worst. What most don't realize is that from a very young age many children with food allergies learn to be aware of their surroundings. As parents we learn to scan a room in seconds identifying and locating potential allergens in order to keep our child safe. The only thing I can compare this to for non-food allergic friends, is when you had a toddler and you visited a friend or family member that hadn't baby-proofed their house yet. When you go to their house you know that you are not actually going to be able to relax and have a good time because while everyone else is kicking back enjoying the conversation, you are constantly watching the outlets, manning the staircase with no baby gate and taking all the chokable objects out of the hands of your exploring toddler. For a parent or a child managing food allergy, when allergenic food enters the room, you are similarly "on alert." A child in class might be watching their peer, wondering "Is that food safe for me?" "Did he/she wash their hands?" "Did they touch the pencil sharpener?" "Did it spill on the table?" If a child has to be on high-alert, then they are not ready to learn. The same alertness that helps children learn to self-manage and self-advocate as they grow, can be

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a detriment in the classroom. Oftentimes, their worries carry over beyond the time at which the eating took place.

3. The classroom is the child's place to work and to learn. It is where they spend the majority of their time. If allergens are in the classroom, this increases the chance of an allergic reaction. There is an increased risk that allergens will be accidentally ingested or that allergens will be on surfaces, teaching materials, and learning tools that the children use. The supporting data shows that 45% of allergic reactions requiring epinephrine BEGIN in the CLASSROOM, not the cafeteria.

Other points to consider:

- Allergens can remain on surfaces that appear to be clean.
- Research indicates that adults touch their faces numerous times per hour and that children, ages 2-5, touch their faces 40 times per hour. This means that a student with an allergy can unknowingly touch their allergen and then touch their eyes, nose or mouth and suffer a reaction as a result.
- Often these measures are put in place at a young age. However, teens and young adults should be given the opportunity to learn in an environment free of their allergens as well. Teens are at a higher risk of a fatal allergic reaction. We need to continue to protect these children.
- Many times, people focus on severe reactions only. However, even a "mild" reaction may result in the loss of time in school, and emotional fall-out for the child. Often when a child has any reaction, they are rightfully sent to the nurse to be observed. During this time they are missing out on important classroom instruction. Often, parents opt to, or are encouraged to, pick their child up from school to be observed at home or taken to their doctor missing even a greater amount of school instruction. Once the reaction occurs, the child may no longer feel safe in his classroom. This impacts the child's ability to learn. Although, some reactions may be unavoidable, we owe it to our children to put in place common sense measures to avoid them when we can.

(4) the emotional and psychosocial welfare of students with life-threatening food allergies as it relates to and is influenced by such students' membership in the school community and how such students are included or excluded from participating in school events, and
When I have observed or been made aware of exclusion, it is often because a plan has not been put in place ahead of time or there has been no priority to make sure all students are included in school events. This is a widespread issue as many school events center around or involve food. However, this issue can be resolved by strong leadership that includes a clear message to those planning events that the priority must be to make sure all children are safely and fully included in school community events.

It is important that a plan to include the child be discussed well in advance of any event. This plan should be initiated by the appropriate school personnel (such as the 504 coordinator) and should not be left to the parent to advocate for. Recently, the 504 coordinator at my daughter's school brought my child into her office to discuss an upcoming dance. Together, they put a plan in place that my daughter felt comfortable with. I was then also asked for input and guidance to support my child. As a result, my daughter was able to fully and safely participate. While the

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plan is an important component, what is equally important is the fact that my daughter felt supported by the adults in her school. The adults at the event were all on board with the plan and were there for her should a problem arise.

Please see, "Food Allergy Tips for PTA Leaders"

(5) how instances of isolation or targeting of students with life-threatening food allergies by other students, school staff or school policy are addressed by the school or district administration.

This is difficult to gauge as research reveals that many instances of bullying go unreported even to parents. However, we do know that children with food allergy are at an increased risk of being targeted and that bullying can have a profound effect on the child's quality of life and ability to perform academically. It is most helpful to again, have education and training for all staff about: food allergies in general, food allergy management, how to identify and respond to incidences of bullying, words and actions that may be harmful to students with food allergy, and how to best support children with food allergy. It is also beneficial to educate all children about the best ways to support their classmates, and to educate parents of non-allergic children about food allergy and about policy. It has been my experience that a positive tone and a firm approach when communicating food allergy policy to the greater school community is most effective.

Please see, "Bullying Facts"

Respectfully submitted, Gina Mennett Lee

Please also include the following resources:

<https://community.kidswithfoodallergies.org/fileSendAction/fcType/0/fcOid/28321765469895236/filePointer/28321765490860175/fodoid/28321765490860153/Non-Food-Rewards.pdf>

[http://allergyhome.wpengine.netdna-cdn.com/schools/files/2014/01/PTA-Leader-Food-Allergy-Tips-](http://allergyhome.wpengine.netdna-cdn.com/schools/files/2014/01/PTA-Leader-Food-Allergy-Tips-One-Page.pdf)

[One-Page.pdf](#)

<http://www.foodallergy.org/file/bullying-facts.pdf>

Gina Mennett Lee, M.Ed.

Owner, Mennett Lee, LLC

www.FoodAllergyConsulting.com

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Gregg and Jennifer Seiderer, Parent, Weatogue, CT

Thank you for the opportunity to share our story and hear our concerns about the lack of administration of epinephrine by trained adults on school buses.

Our son, Eli, has a life-threatening allergy to peanuts. He has experienced anaphylaxis -- lips swelling, wheezing, throat closing -- with one bite of peanut butter. He started kindergarten at

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Central Elementary in Simsbury on August 27, 2014. We initiated conversations with the school about Eli's peanut allergy in February of 2014, a full six months before he was to start school. The one issue that was not resolved until August 25th, two days before school started, was transportation to and from school. When we first met with the school in April of 2014, we were told by the Simsbury Director of Health Services that she personally conducts yearly training for bus drivers on the signs and symptoms of anaphylaxis. When we asked if this meant that the bus drivers would actually administer the epinephrine, we were told that they would not. Their emergency protocol instructs them to pull over to the side of the road and call the Salter's Express Company dispatch, who would call 911. When we indicated that this was not acceptable because anaphylaxis can kill a child in minutes, we were told by the Director of Health Services that "educational law" prohibits bus drivers from administering epi. We asked for a citation for this law; we never received any such citation.

The Director of Health Services then recommended that we contact the Transportation Coordinator to see if Eli could be picked up last and dropped off first, thus minimizing the amount of time he would be at risk. When we contacted the Transportation Coordinator via phone, we were told that they would not pick up Eli last and drop him off first because "that does not make sense." The Coordinator was unwilling to even discuss it. She indicated that based on where we live, Eli would be on the bus for a half hour each way and if he is "that allergic," he should be able to self-administer the epinephrine. We pointed out that not only was he only five years old at the time, but that anaphylaxis often impairs breathing and causes a drop in blood pressure and loss of consciousness, so we would be reluctant to have even a much older child self-administer, let alone a kindergartener. We also said that this was not approved by his allergist. The Transportation Coordinator told us that bus drivers are not allowed to administer epi per the Director of Health Services, who tells them that every year. The Coordinator said she doesn't know why they are prohibited, whether it's because of medical liability or some other reason. When we asked how children in wheelchairs or with other special needs are accommodated, the Coordinator said that they are handled by Special Services and have a PPT plan. We asked what this was and she said it is a Planning and Placement Team. Once that plan is in place, she is notified to remove the child from her transportation list because Special Services takes care of the transportation. We then contacted the Director of Health Services again to tell her that things had not been resolved with the Transportation Coordinator and that, under the Section 504 plan for Eli's disability, it was the school's legal obligation to ensure safe transportation for Eli.

On August 22nd, five days before the start of school, we met with the school again to finalize and sign off on Eli's Section 504 plan. At that meeting, nothing had been resolved about transportation, though the Director of Health Services and the newly hired principal both said that they knew it was their responsibility. They indicated that if they had to, they would hire an epi-trained paraprofessional to ride the bus with Eli. On August 24th, the principal called to inform us that they had, in fact, hired a paraprofessional to ride the bus with Eli. We thanked her and indicated that once that was added to his Section 504 plan, we would sign off on it. Later in the day on August 24th, we received four voicemails from the Special Services Supervisor, asking us to call her about transportation. We contacted the principal instead, who

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told us that Salter's Express Company would not allow the paraprofessional to park her car at Salter's lot in order to get on the bus at the beginning of the route. The school had then arranged with a neighbor of ours to allow the paraprofessional to park at their house, but Salter's would not pick up the paraprofessional at a stop with no children getting on. The principal then asked if the paraprofessional could leave her car at our house every day and get on the bus with Eli but we said no as this singles him out and makes him a target for bullying. She said she would get back to us. From the final 504, which was not signed until 8/25, the day of kindergarten orientation: "All bus drivers will be in-serviced annually on the signs and symptoms of anaphylaxis including implementing Simsbury's emergency response procedure.

The existing policy of no eating or drinking on the bus will be strictly enforced. Eli will be sitting in the first few seats that are designated for Kindergarten students. Eli will have an EpiPen trained employee available for transportation to and from school. Parents will be available for transportation on an emergency basis." On August 26th of 2014, the day before school started, the principal called and told us that the transportation had been worked out. The paraprofessional would park her car at Simsbury High School and walk to Salter's lot (approximately two blocks away) to board the bus at the beginning of the route. She would get off the bus with the students at Central and reverse the route in the afternoons, returning to Salter's and walking back to her car at the high school. Since the beginning of that school year, there were three occasions when the paraprofessional was not available. On the first occasion, we were not notified ahead of time and Eli actually boarded the bus. The bus driver waved down Jennifer and demanded that she remove Eli from the bus, saying that she "couldn't take him." Eli was upset and crying, and Jennifer had to drive him to school. On two other occasions, the school called right before the time of pickup, asking Jennifer to drive Eli to school. On numerous other occasions, Jennifer noticed the Central School Nurse riding the bus to accompany Eli instead of the paraprofessional. The principal confirmed that the school nurse is the backup for the paraprofessional.

In first grade in 2015, Eli still had a paraprofessional on his bus. That year, we had to specifically request in his Section 504 plan that the paraprofessional watch for food being eaten on the bus around Eli. Despite the fact that the policy is that no food is eaten on the bus, on at least two occasions, the child sitting in the seat with our son ate food from home.

This year, Eli no longer requires a paraprofessional on his bus as he has gone through a desensitization treatment. While it has been completely life-altering for our family, this treatment may not be appropriate for all children with life-threatening food allergies. For that reason, we still believe it is imperative to address the issue of the administration of epinephrine by trained adults on school buses and we are extremely grateful to the task force for considering the issue.

A few points that we believe are important to keep in mind:

- It's not enough to say that the bus drivers must be trained on the signs and symptoms of anaphylaxis and how to administer epinephrine. In Simsbury that's already happening but there's nothing that mandates that the drivers WILL administer epi. The issue of liability or lack

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thereof should be addressed because we presume this is one of the biggest obstacles to implementation by bus companies.

- Emergency protocols should be changed so that epinephrine is administered immediately. Only after that is done should 911 or dispatch be called, whichever is the most expedient.
- Updated anaphylaxis protocols for the bus should apply to only those children who are already identified as having life-threatening food allergies and who already self-carry their own epinephrine as allowed by CT state law. Due to high cost, quick expiration dates, and temperature sensitivity, it is not practical for stock epinephrine to be available on buses for those children who are not already diagnosed.
- Children who are identified according to the bullet above should be identified as such to their bus drivers. One solution might be to have their photo posted where the driver can access it. The photo would have all identifying information on the back so as to protect confidentiality. Information should include but is not limited to: name, age, what they are allergic to, and where their epinephrine is located. This information should already be available as the schools should be completing an emergency action plan for all children with life-threatening food allergies (even children who do not have Section 504 plans should have this document).

Thank you for your consideration and please don't hesitate to contact us if you need more information.

Sincerely,
Gregg and Jennifer Seiderer

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Juliette Donovan, Advocate, Southport, CT

Dear Task Force Members:

As a child who has grown up with many food allergies and who is now 15 years old, I have noticed many things throughout elementary school and middle school that have been very upsetting.

In elementary school, for the first four years at every lunch time I had to sit at the peanut-free table rather than sit with my friends to eat--which I hated. I felt alone and isolated. Eventually in fourth grade, I asked my mom to talk to the nurse to allow me to sit at a regular table because I just wanted to sit with my friends at lunch. By the fourth grade, my friends knew me and my needs but sitting at the peanut-free table, I was being separated from my friends just because of a few allergies. Instead of making kids feel singled out and different, a simple solution is to teach kids about allergies and how to adapt to their peers who have allergies. Kids want to help their friends but they first need the education to know how to help.

Another major problem I noticed throughout elementary and middle school is that teachers single out kids with allergies. Every single year when the holiday season would come around and students would ask the teachers why we were not allowed to bring food to the class

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parties, the teachers would blame it on the kids with allergies. Once before a holiday party, I had a teacher actually say to the class, "And we're not allowed to bring food to the party tomorrow because those allergy kids ruin it for everyone." I remember just turning completely red and having some of my friends who knew about my allergies look over at me. At the time, I felt completely singled out and it was definitely not the first time something like that had happened. If students and teachers had been taught about allergies and how to deal with peers having allergies these situations could have been avoided.

I thank you for looking into food allergies in schools and for considering the point of view of students with food allergies. In the end, we just want to be considered students.

Sincerely,

Juliette Donovan
Southport, CT

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Kathy Neelon, MS, BSN, Nurse Coordinator, Wallingford, CT 06492

Subject: Food Allergy Comments

First I would like to stress that I don't think we need to implement one more directive legislatively regarding food allergies. We have an excellent document provided by SDE and if followed you can keep all students with food allergies as safe a possible. We can't keep anyone 100% safe from anything but if we follow the plan the students can be safe. We implemented our District Plan in 2006 based on the SDE document and have been extremely successful with keeping students safe with life-threatening food allergies. We educate all staff every school year with great success. We have only had 1-3 incidents at the most per year which we report to the State every year. All incidents were high school students who ate something and new they should not have eaten the food or the student had an new unknown allergen. Last year out of over 230 students with LTFA none needed to receive their EpiPen. Before we go changing anything where is the recent data to show that students who need an EpiPen are not getting them when needed. In addition, we have never had to administer an EpiPen on a bus. If legislation requires training bus drivers the cost of training can't be pushed onto the school nor should the training have to be done by the schools. It would be another unfunded mandate of which I would not agree. Again, where is the data to support the need for this training. Regarding the legislation that a parent has right to opt-out of the school providing emergency Epi to children by trained qualified staff is an Act that clearly has not been thought through. The legislation requires schools to train qualified staff to treat a student for a life-threatening condition and then you allow the parent to opt-out of allowing the trained staff not to administer life-saving medication.....not sure what the logic is in this requirement. Most parents have no idea of what we are explaining to them when informed of this option.

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Unfortunately, in our district we had hundreds of parents opting out this year and the school nurses had to call each one and explain what they were opting out of and all but a few reversed their decision. If the law wants us to train qualified staff to treat a suspected life-threatening condition and a parent opts out are we not supposed to treat their child if they present with life threatening symptoms? This opt out option then still puts some children at risk for not being treated when needed for a suspected life-threatening allergy. You really can't have it both ways. You are asking an unlicensed person (I have a problem with this in itself) in an emergent situation where they have to react quickly to review a list of students whose parents don't want their child to receive life-saving medication and now what do they do beside call 911.....as I have said this is not good practice and all the ramifications have not been thought through. The intervention should be that if they are trained to respond they should be allowed to respond to all students.

Thank you,

Kathy Neelon, MS, BSN
Nurse Coordinator
Wallingford, CT 06492

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Kim Zolvik, Parent

Hello,

I am a parent of a child with many life-threatening food allergies and I profusely thank the Task Force and the State of Connecticut for giving food allergies in school the attention this disability desperately needs. I'm listing below our experiences/comments from the last year and a half, trying to be as brief as possible.

New personnel: The new principal (2015-16 school year) did not know about the bus policy for food-allergic kids (drivers are trained in administering epinephrine and kids are allowed to self carry) when I asked about it during a 504 meeting. She told me she'd look into it and get back to me which she did, telling me it's not possible for my daughter to take the bus. She also didn't know a food allergy regulation (reasonable accommodation for food at a school event) when she planned a game using marshmallows. With these occurrences, it appears the district didn't educate this new principal as to what the policies and regulations are.

New students entering the school district: After registering my daughter for Kindergarten in the spring, I quickly realized she wasn't "flagged" as a FA student for orientation. All new students were assigned to classrooms and after arriving to hers, I quickly saw Gold Fish on the floor. I asked if this room had been cleaned and the answer was no. I asked if they knew my daughter has food allergies. Again, no. I requested she be moved to a different classroom and she was.

Staff lack of FA knowledge (continuing from above): On the way to the room, the teacher/aide asked "Are her allergies contact?" I replied "It doesn't matter if they are or not, if she touches an allergen then touches her mouth, that's a potential ingestion." This was also asked in other

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conversations and 504 meetings and my response was the same every time. Clearly, there's a lack of staff education. All staff at this school are trained in epinephrine administration and signs of anaphylaxis but it appears they are not trained in anything beyond that. Hand washing: Both Connecticut and CDC guidelines state students and adults entering a FA classroom wash their hands upon/before entering? This school absolutely refused to implement this practice even after four 504 planning meetings and the presentation of these guidelines to them. The district's Director of Pupil Services was present for the last meeting, per our request, and stated absolutely no and that he discussed this with the town's superintendent and they deemed it "not necessary". Safe snack lists: Unable to give a safe snack list to parents through the school. I asked but was given a firm "No" after a few parents asked me for one. This has been practice in the past but appears to have been inconsistent and is now stopped by the new principal.

Tree nuts/peanuts not allowed in classroom: When my daughter started kindergarten, I met with her new teacher to discuss her allergies and what's needed in the classroom. She told me she replaces nuts brought in by kids for snack with crackers she keeps in her classroom for this purpose. BUT at a 504 meeting, I asked about this again to confirm and the teacher said "No, I don't replace any snacks." The principal then said they "cannot take food away from a child." I asked the teacher why she told me this during our meeting and she said "That was before the [practice] changed." Again, the new principal changed a practice.

Food allergy alert letters sent home to all students' families in the class: This year we added to our 504 the FA alert letter is to be sent home in Spanish in addition to the usual English. Other families at the school have had this for a couple years now BUT the school doesn't offer it to any other families. We had to request it during a 504 meeting. They balked at first but we gave an example of another child having this accommodation. Only then did they agree to it. A couple weeks later, I passed the nurse's office and noticed quite a few index cards on it. All had one word on them, "nurse" translated into all the languages spoken by students' families. The school should be offering to have these letters translated for ALL languages spoken by classmates' families.

Establishing accommodations prior to the 504 planning meeting and without parental input or consent: After a couple weeks in the current school year, we found out our daughter was being moved from her desk to a side table to eat her snack. The school social worker casually informed me of this during a quick hallway conversation. I asked why she was being moved when a letter was sent home to parents alerting them of the allergens. She replied "Well, she's the one with the allergies isn't she." Note these allergen alert letters do not state to not bring the allergens for snack but only to be considerate of the student with allergens.

Substitute nurses: I dropped a form off one morning and found the regular nurse wasn't in. I introduced myself to the sub nurse and asked how often she is here. Her response was "at least once a month." I indicated who my daughter is on the food allergy board (in full view of anyone who goes into the nurse's office). She didn't know my daughter but said she'd "seen her around." I then told her my daughter had a cold over the weekend and the regular nurse was

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informed yesterday (Monday) and checked her for asthma. This nurse didn't know and made it obvious she wasn't informed of this. What is the process/protocol for sub nurses and teachers? How is pertinent information passed on? Note parents aren't notified if the school nurse is out. If you email her, the sub nurse has no access to that email account, hence not knowing if there is a child who needs attention during the school day.

Allergy alert door signage: When my daughter started kindergarten, the signage was a large, two-foot-wide circle with a peanut and the standard red circle and slash over it. These signs were quite visible from a distance and once closer, one could easily see the complete list of allergens in that particular classroom. This graphic visual indicated that the listed allergens were banned from the classroom. During our 504 meetings, we were repeatedly told they "cannot take food away from a child" when we asked about tree/peanut restrictions in the classroom. Frustrated during one of the meetings, I asked "Then why are there signs indicating allergens are banned? These definitely give the impression they are which give a false sense of security. As our daughter learns to read, how will she interpret this?" They quickly changed to an 8.5 x 11" sign with a cute cartoon animal image taking up 80% of the space, leaving a small amount for the actual allergen list. This sign is visually lost when on a door with many posters/announcements/etc.

Overall experience: Our first year of kindergarten was the most confusing and difficult time. Being new to school and our daughter's rights under the ADA, we found it very hard to get answers about appropriate accommodations under the law from school staff. The district's policy is to reach out to FA parents and inform them of their rights under the ADA - this did not happen. We had to request a 504 meeting. Our impression from the school during and after these meetings, the principal and social worker in particular, was all accommodations fall on to our daughter. All other students would be inconvenienced if made to wash their hands upon entering or move to a different location if they had allergens for snack, for examples. School staff would be inconvenienced if asked to wash their hands (even though this would be a preventative practice for spreading germs during flu/cold seasons as well as preventing allergen exposure!). Teachers would be inconvenienced if students needed to wash hands in the morning as this would take away from instruction. We were baffled that this staff would prefer to have - and chose to have - a severely allergic student in an environment that was unsafe when the simplest of practices would make it the utmost safe.

Time will only tell how our daughter fare's during these young years at school. Not yet developmentally capable of fully understanding what this all is, she is having difficulty interpreting and navigating situations in school. And I don't feel the staff are receptive to hearing about these things. We are currently dealing with reading and math issues and do wonder, are these the result of not being able to concentrate on instruction because she's worried about allergens? Can she truly be learning if her focus is distracted because her classmate next to her just had peanut butter crackers for snack? Is she actually scared to be in her classroom?

Sincerely, and I thank you again for your dedicated work,

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Kim Zolvik

p.s. I purposely left out the PTA. That's a whole other kettle of fish. The district's regulation states "When extra-curricular activities and/or PTA events incorporate food, consideration and reasonable accommodations will be made for students with food allergies." I laugh. This has not happened.

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Betsy Craig, CEO and Laurie Thomecek, MPH, Director of Education of AllerTrain by MenuTrinfo

To Whom It May Concern,

AllerTrain by MenuTrinfo is a leading company providing accredited nutrition & food allergy solutions. AllerTrain by MenuTrinfo is dedicated to helping foodservice operators including institutions, restaurants and catering operations protect the lives and health of customers by meeting and exceeding nutritional labeling and food allergy regulations as required by law. The company offers an entire suite of food allergy courses including AllerTrain™ and AllerTrain Lite™, the only ANSI accredited food allergy & gluten-free training classes in the food service industry.

To understand the vast importance of studying life threatening food allergies in schools, it is important to understand the increased rate at which food allergies have grown in the United States, the severity of food allergic reactions, and the growing public health concern food allergies are becoming.

Researchers estimate that up to 15 million Americans have food allergies. According to a study released in 2013 by the Centers for Disease Control and Prevention, food allergies among children increased approximately 50% between 1997 and 2011, and the number of people with a food allergy is continuing to grow with no clear answer as to why. This potentially life ending disease affects 1 in every 13 children in the U.S. resulting in an economic cost of \$25 billion per year for children's food allergies.

Food allergies are unpredictable in nature, and mild symptoms can quickly become severe without warning. Every 3 minutes a food allergic reaction sends someone to the emergency room, resulting in over 200,000 emergency department visits per year. Additionally, 25% of people's first food allergic reaction happens outside the home. This signifies the intractable importance of employees in eating and drinking establishments to be adequately trained in food allergy awareness and safety protocols, should a person go into anaphylactic shock in their establishment.

Cross contact and cross-contamination are two of the biggest concerns for food allergic individuals dining out in public or in schools. The only way for a person to remain protected from their allergens(s) is to strictly avoid them; even a trace amount of an allergen could result

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in a severe reaction. In order to accommodate and ultimately protect the health of food allergic diners and students, employees working in the food service industry must understand the proper safety measures and protocol for completely eliminating the potential for cross contact or cross-contamination from occurring in their establishment. Receiving accredited training and passing a test thereafter will prove employee's competency of the course material surrounding food allergies, and hold them to an enhanced standard of safety in their schools and establishments.

By law, under The Americans with Disabilities Act, food allergies and anaphylaxis are considered a disability. Therefore primary schools, secondary schools and Universities alike must make appropriate accommodations for those living with food allergies. On top of severe physical implications, living with life threatening food allergies can have major social, emotional and psychological implications for a child. It is imperative that students feel as secure and confident as possible eating in their school's cafeterias, without having to worry about their physical health. Public education is a fundamental human right and if this right is infringed upon because of the ignorance of educators whom students put their physical and emotional trust in, this is unjust.

By setting a higher standard for Food Allergen Awareness Training in eating and drinking establishments, and requiring all food service providers, including public venues and schools to receive accredited food allergy safety training, the general public, schools, restaurant owners and operators, and food allergic diners will benefit in the following ways:

- Food allergic individuals will feel confident and safe dining out and going to school if they know the establishments they eat in are willing to accommodate them and are trained in food allergy safety.
- Eating and drinking establishments will minimize their risks by having a food allergy management program for their restaurant, and gain greater customer loyalty.
- Ultimately, the risk of anaphylaxis occurring will be reduced for those living with food allergies if the establishments they frequent are safe.

Betsy Craig, CEO and Laurie Thomecek, MPH, Director of Education, along with the entire AllerTrain by MenuTrinfo team urges the Connecticut Task Force to further study food allergy management in schools and seek mandated food allergy safety training regulations sooner than later.

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Linda Valletta, RN Washington Montessori School

My name is Linda Valletta and I am an RN at the Washington Montessori School in New Preston CT. I have worked here for 11 years. Currently at school there are a total of 237 children 16 with life threatening food allergies. 13 children with peanuts and tree nut allergies, 1 with shellfish and 2 with fruit. As the nut allergies continued to rise, we became a nut free school. This allowed those children to learn in a stress free environment. We also established a fruit and vegetable snack policy in preschool through third grade. These snacks are brought in whole and

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prepared in the kitchen so that there are no worries about cross contamination. Epipens are kept in the health office because it is centrally located between regular classrooms and special (PE and Music) classrooms. If a parent requests, an extra set is kept in the child's classroom. All teachers are trained by myself on signs and symptoms of an allergic reaction and how to use an epipen. This is repeated 1 on 1 for field trips and the epipen goes with the teacher in charge. I have had to administer an epipen once at school and the student did well. It is pretty scary when you have a child who is in such distress but It always amazes me how quickly the epinephrine works. Of course the most important thing with food allergies is prevention. Feel free to email or call me if you have any questions.

Linda Valletta, RN Washington Montessori School

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Julie Nintzel , Parent

As a parent of a hypoglycemic child who's daily nutritional needs are best served/require access to nut based nutrition I am highly upset these meetings took place without making the schedules agendas more publicized. I've been checking on the CGA website and nothing was posted on the state website till now. My daughter's dietary needs are best served by some nut based nutrition; she is dairy sensitive, so we must say "no" to just adding more dairy; and "no" to just adding more fruit which can spike sugars only to plummet again; as she grows, her hypoglycemic tendency has worsened. She needs a protein source that she can and will eat. She has a doctor's note to always have access to extra food & snacks throughout her day not just designated lunch time.

She has been held in the hospital twice in her 10 yr life for unstable blood sugars, and once slipped into an unconscious coma like state while in the hospital. FYI, Hypoglycemic attack, can look to untrained teachers' eyes as just an unfocused tired distracted kid, and lack of understanding can result in hypoglycemic coma- which can be just as dangerous and deadly as a nut allergy reaction. My daughter needs to be able to have the food I pack for her in her packed at home lunch that will keep her blood sugars up & steady and even so she can be ready to focus and learn. I highly object to any effort meant to be taking CT schools completely "nut free", as that will force the school administrators, teachers, (adults in the building) to bully my child if the lunches I pack aren't labeled to meet whatever strict guidelines you are set to meter out. Adults (school employees) bullying a child and throwing out their food can never be allowed or condoned. I can't stress it enough that we cannot have adults policing my daughter's (or any other child's) lunches and cannot be throwing out her or any other child's food!!! As your minutes of previous meetings are ambiguous I don't know what the proposed plans or changes are. This is beyond upsetting that there wasn't a way to have been kept up to date on these back channel meetings. I would never want to put a nut allergic child at risk, but there are cases were where children (like my child) could or would be harmed by a totality ban on nut based nutrition in schools. And while yes there might be a social stigma of allergy bullying, the State can't just try to remedy that by causing adult school employees to be bullying and persecuting non allergic children over what's in their lunches. Anecdotally, my daughter will,

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and often has (as kids do) put herself at risk by simply not eating at all/or refusing to eat what she deems gross. I need be able to access giving her foods that she will consume regardless of what a package label says or what facility it was made in- regardless of whether or not every single food item is properly labelled "nut free." I say again you need to figure the consequences of a ban, a total ban in all school cafeterias of nut based nutrition food items would ultimately force adult school employees in the public schools to harass and bully and endanger my child and others like her. Completely wrong and unfair! The bullying would simply shift- Harassment BY THE ADULTS is wrong. How would she and others like her feel protected and advocated for if adults are ordered by the State to throw out her food.

Again my child has dairy sensitivities which means no to just offering her a cheese sandwich from the cafeteria or yogurt or drinking more milk, cold cut sandwich =gross to her so she won't eat that, and what is the cure for hypoglycemia?? She needs to eat - often. A balance between a protein she can and will agree to eat, balanced with a good carb. Please don't say just buy lunch, because what is offered is tasteless & gross and she won't just eat it. So I need to able to pack at home what she'll eat from home without any more State hindrances. Side note-she has a healthy PB sandwich today for lunch, and PB dip with pretzels for snack, along with other healthy balanced foods. Nut butters are a good protein source slowly digested with healthy carbs. The systems currently in place for protecting allergic children work, while also providing a place my child can also eat what's best for her. Please say NO to making all Connecticut schools nut free.

Most Sincerely, Mrs. Julie Nintzel - Concerned Parent, Seymour, CT

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Pam Minicucci, Parent

Good Morning,

My name is Pam Minicucci and I have 2 school aged children with food allergies. I was also involved in the advocacy during the 2009 legislative session in passing S.B. 755: An Act Concerning the Use of Asthmatic Inhalers and Epinephrine Auto Injectors While at school.

I am a Former Emergency Medical Technician with 15 years' experience under my belt, currently a school bus driver for 10 years, and a parent of two food allergic children ages 12.5 and 14.5. As you can see by my credentials I live through every aspect, every day, of what this committee is about. I have a personal experience, just recently, while one of my children went on a field trip while at school. I admit that as my children mature to young adults, I have taught them to self-advocate when they were young enough to somewhat understand, and now I ease them into totally self-advocating for themselves, although I still worry and remind them, "do you have your allergy kits?", "yes mom" is always the answer. That will never stop as long as I'm alive. But to my teen daughters, they no longer want their mom or dad to chaperone their field trips. My 14 year-old was diagnose with tree nut allergy at age 3 and my 12 year old was diagnosed with peanut and tree nut allergy at 3 months of age.

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We get that, and we need to let them do this on their own, while us parents secretly feeling useless because there is longer the need of a watchful eye of mom or dad to linger over them like they needed when they were younger. So this brings my story of a field trip that my 12 year old recently took to Hartford to see a Christmas play. As a bus driver, I have never driven a field trip when either of my kids were part of it. The reason being if they had an allergic reaction, which would be there to drive the Bus? You just can't use anyone; you have to be a CDL holder with a school bus endorsement. With that said my daughter went to school that day, and I had a medical appoint at Yale (about 6 hours long). About two hours into my appointment I get a text from daughter's teacher, who is chaperoning her group and already enroute to the venue. She informs me that there is no place for the students to eat their lunch and they will eating their lunches on the bus during the ride back to school. She had asked me if I wanted to have my daughter seated towards the front of the bus. I let her know that being confined inside a school bus with the windows closed and the heat on will make no difference where she sits. She would have an allergic reaction if there is peanut butter sandwiches and peanut products consumed on the bus. Mind you, I am employed by the bus company that provided the transportation for this field trip, 7 busses in all were used. There are notices hung in all the busses that state no eating is allowed on the busses due to food allergies, so really they were breaking the rules by allowing students to eat on the bus. The teacher was going to take a poll as to who had peanuts/peanut butter sandwiches. I also called the school principal letting her know what was going on. She apologized to me and was under the impression that students had to get bagged lunches from the school cafeteria, because they would have made sure they were peanut- free.

But that wasn't the case. The teacher on the bus and the principal collaborated with each other and once they came up with the total of peanut products brought onto the bus, the decision was made as to whether or not to separate the students with peanuts from the non. I would have had a bigger problem if my daughter's friend had brought peanuts in her lunch and was made to move to another bus from my daughter. My child has come a long way from the social isolation and stigmatism that goes along with food allergies and for many years she struggled socially. It would have been detrimental to her if she had to be separated from her friend, all because of failure on the schools behalf not to previously find out what dining arrangements would be. As a frantic last minute decision to eat on the bus, they failed to take into the consideration of all the food allergic students, even the ones not in the school, grade or field trip.

So you wondering what do I mean by that? Because I am a school bus driver, I know that all of the busses used for the field trip will now have to be cleaned before the dismissal of the high school, middle school and elementary school students who all ride those 7 busses twice a day. Did I notify my place of employment about the eating situation that day? I sure did and also let them know all seats and handrails would have to be cleaned to prevent cross contamination, especially for the youngest of students because they still put their hands in their mouths. Were the busses cleaned? Probably not. My daughter that day was able to enjoy the ride home while sitting beside her friend chatting and having lunch. She is growing up and I am preparing her for

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the real where she will no longer be protect by her 504 Plan or by her dad and I, but for the many elementary students or newly diagnosed students no matter what their age, they need to feel safe while at school and the school bus really is an extension of school and must have protocols in place for these allergic students. My bus is longer used for athletics because coaches bring food on the bus all the time.

My daughter had an allergic reaction one time, and she was just a toddler at the time. My two children are not the only children with food allergies on my bus. I do notify a parent if I'm not driving because part of this students 504 plan is to make sure the seats are wiped down in the morning and again in the afternoon before this student comes on board. I let them know when I'm not going to be there because I cannot guarantee that mother that word would get passed down to the spare driver about cleaning the seats. Remember my children are food allergic too. So at least those parents can decide if their child should take the bus that day. As a school bus driver, I wouldn't hesitate in a heartbeat to administer an epi pen. I always carry extra on me. You don't realize how relieved parents are when they find out my background if their own child carries an epi pen.

I can only speak for the company I work for. If a student is having a medical crisis, we drivers have to radio to our dispatcher, let them know what going on, and then the dispatcher has to call 911. Sometimes there is a lot of radio traffic and you can't get through the dispatcher in a timely manner. My bus route has a few "dead spots" in areas where I can't receive or transmit radio communications. School bus drivers are not trained in any kind medical crisis, i.e. how to recognize when a medical arises on the bus or in CPR or how to help a student who is choking or is a student is in some kind of distress. As a matter of fact we are told not to in engage in conversations or make physical contact with any child for any reason. Precious live saving minutes can be lost and terrible outcomes can happen. If a Driver has the tools and knowledge, in this case epi pens on board and be trained to administer, no student who is on a school bus should have to die because of anaphylaxis. Yes there are parents who still do not let their young children carry epi pens; they think they are too young. Many parents still don't know that their kids have a right to carry. Both my kids have always carried since entering school at age 5.

Thank you for allowing me to share my story,
Pam Minicucci

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Patricia Krin, RN, MSN, FNP-BC, NCSN, FNASN, retired school nurse

I am a retired school nurse, who worked in school health for over thirty years. I am a registered nurse, a certified school nurse teacher, a certified nurse practitioner, a nationally certified school nurse, and a Fellow of the National Association of School Nurses. I am glad to see that there is a task force in place to look at the issue of life threatening food allergies in schools. I sincerely hope that the outcome of these discussions will benefit all involved.

When I read parents' comments I feel their concern for the safety of their children. I think it is safe to say that everyone, schools and parents alike will benefit from the outcomes of this task force.

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One of the things that I would like to point out to the committee and to parents who are involved in this is that school nurses are working under qualifications that were written in 1982. While it may not seem relevant to this discussion, I will say that school nurses do not come into school knowing about food allergies, or many of the other chronic conditions that students face in school today. There is no preservice education requirement or required orientation for school nurses as there is for every other professional who works in education. Most nurses who work in a specialty practice, such as intensive care, emergency room, operating room, and many others have an extensive orientation prior to and inclusive of their employment. That is not the case with most school nurses.

Many school nurses do not have supervisors who are nurses, and consequently have no mentors when they embark on the journey. There are no real educational or certification requirements for school nurses. Every other professional who works in the school is required to have a state certification which shows they are prepared to perform in the job, not so with school nurses.

Perhaps one of the outcomes of this task force should be to ensure that every school nurse is prepared to provide safe and effective care for the students that they serve. That can only happen if the nurses are educated about all areas of school health when they enter the educational system or at least within the first year of employment.

We are talking about children's lives. When I read parents' comments involving unpleasant experiences with school districts, I can see that in many cases there is a lack of understanding about what constitutes safe care by some administrators and some school nurses. While this task force is specific to food allergies, there are many students with chronic conditions who would benefit from having school nurses who are educated about and understand the specialty of school nursing. Every student deserves a well-educated, well prepared school nurse. No one can know everything about everything, but we need to ensure that school nurses are well prepared to handle needs of their students. Current laws and regulations do not support that concept.

We think there about 1100 school nurses in the state of Connecticut. I am not sure that anyone knows how many for sure. Only about 400 of those nurses belong to their specialty organization, so they do not always get the information that goes out to school nurses. Many school nurse supervisors do not belong to their specialty organization. These nurses do not get notification of all the continuing education opportunities that are available to those who belong. They do not get the journals published by the National Association of School Nurses. We cannot even contact the nurses who do not belong to their professional organization as there is no database of contact information of school nurses. The organization does not have access to contact information for nursing supervisors, so it is impossible to provide information that would help school nurses and school nursing supervisors stay aware of programs, emergent information or other helps that might otherwise be available.

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There is national certification available for school nurses. This is an exam that nurses sit for and shows that the nurse who has passed the exam has the needed expertise to function well as a competent school nurse. Only 76 of Connecticut's school nurses have that certification. I urge task force members to consider the importance of school nurse competency in dealing with all students and especially those with chronic health conditions when looking at the desired outcomes of this task force.

Thank you for your time and talents on this task force and for your consideration of my comments.

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Phillips, Jeanie

From: greer902923@yahoo.com
Sent: Friday, October 21, 2016 11:43 AM
To: Phillips, Jeanie
Subject: Public Comment - Food Allergy Task Force
Attachments: ShermanSchoolCelebrationsProceduralGuidelines2014.pdf; Food_Allergy_Policy_&_Guidelines_for_Food_Allergy_management2014 (1).pdf; Gina Mennett Lee Letter and CV.pdf; BOE June 4 (1).pdf

Dear Food Allergy Task Force,

<< I would like to preface this long letter by stating that today, we are in a good place with our school, we have a 504 plan, and due to the 504 provisions and the teachers and school nurse, our food allergic child has largely been included and safe at school. But the journey to get to this point? Three-plus years of unaffordable legal fees, 504 meetings, medical expert fees, school board meetings, online bullying by other parents, verbal harassment at Board of Education meetings, and countless powerpoint presentations and research. We can do better as a state and I believe this task force can help protect parents and students at little to no cost to taxpayers. In talking to other allergy parents this dance happens over and over again in every district, and not even close to all parents are able to take it to the finish line and end up with a satisfactory result. Other parents are understandably afraid to effect meaningful change and cave to the majority opinion due to a fear of being shunned. >>

No one ever imagines that they will have a special needs child. When you first find out your child has a food allergy, it's denial combined with optimism "...well, it could be worse" or "it's not that severe". As the reactions occur, and the severity increases, and ancillary health problems appear (More types of nuts! Traces of nuts from cross contamination causing anaphylaxis! Asthma! Eczema!) the visits to specialists increase and it gradually becomes clear that life will, for the foreseeable future, be forever marked by an uneasy détente with food.

As our older child entered our town's only school, we aimed to use the experiences as "lessons learned" and discussion points with the school administration to ensure that our three-years-younger child would be able to attend school safely. We were appalled at the sheer amount of "reward candy", cookies from the PTO for boxtops, unplanned and planned store-bought and homemade party food that crossed a kindergartener's path (and in the grades above as well, which I learned about through collaboration with other parents).

At the end of the first year in spring 2013, another (non-allergy) parent and I sat down with the administration and presented them with a powerpoint about how the deluge of food was not only endangering and excluding children dealing with medical conditions (allergies, diabetes) but it was setting a poor example for wellness and healthy living for all students. We included copies of procedures from other area schools with strong wellness practices and food-free celebrations. The school administration took this to heart, perhaps because one of the administrator's children was recently affected by diabetes, and instituted a food-free celebration and birthday procedure for the following 2013-2014 school year. This was met with an angry uproar by the town community. A member of the Board of Education actually started a petition against the school, which garnered 110

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minutes from a country hospital and 30+ minutes from a major hospital. We drive to and from school but not every parent has the ability to arrange for this.

So in a nutshell, in the State of Connecticut, unless a parent has a high level of professional skill, a medical team on standby who is willing to spend time on non-office visit work, ample resources, and adequate networking abilities, their child's safety and inclusion at school is subject to the political whims of the town they live in, majority opinion of the community backed by taxpayer dollars "for legal fees" set aside to fight change, and malleable policies and procedures that appear to be compliant with Connecticut's rules, but in reality, they are mostly merely compliant with a rule that requires no content of any sort be included in the policy.

Hopefully you can help by putting the above CDC best practices into a "minimum content for allergy policies" requirement for all Connecticut schools. Backed by real consequences if schools do not comply. Otherwise, it will not happen, as evidenced by the parents who are having the same discussions and battles in nearly every Connecticut school district to secure free and appropriate public educations in the least restrictive environments for their LTFA children.

It should not be the case that the only children who are protected are those whose parents devote years and funds towards affecting change.

Sincerely,
A Connecticut Public School Parent

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Paula Paolino, Parent, Woodbury, CT

To the Members of the Task Force to Study Life-Threatening Food Allergies in Schools:
My child has a life threatening food allergy.

In August 2010, I enrolled my child into Bethlehem Elementary School (Region 14). Prior to enrolling my child, I checked the schools website for information regarding allergy management as I did not want my child to be segregated at lunchtime. I could not locate any information on the website in regards to cafeteria seating arrangements.

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During the new student orientation, I inquired as to the accommodations at lunchtime for children with a LTFA. I was advised to meet with the nurse, who met with me in front of all the parents, no privacy was afforded, and Sue Williams, BES School Nurse informed me that it was mandatory for my child to sit at an allergy free zone at lunchtime. I explained to Ms. Williams that I did not want my child segregated at lunchtime but she refused to consider my request and stated it was “district policy, I had no choice.” I pleaded with her to honor my request which prompted her to relay stories of all the things that could go wrong if I didn’t segregate my child at lunch.

I find it interesting that this district policy was never in writing and not posted on Region 14’s website.

For three years I watched my child suffer emotionally, socially and physically from the stigma of being forced to sit at an allergy free table during lunch, segregated from his peers. The negative impact this arrangement took on my child was unbearable and caused me a great deal of anxiety and stress as I felt helpless. As I watched his self-confidence and self-esteem dwindle, I was desperate to get him off the allergy free table. In the summer of 2013, I enrolled my child in the New England Food Allergy program in which I received a note from Dr. Jeffery Factor stating that it was not necessary for my child to sit at an allergy free zone during lunch and he also stated that he does not favor an allergy free zone. I sent the note to the school nurse prior to enrolling my son into the 3rd grade.

As a courtesy, I contacted the mother whose child also sat at the allergy free table with my son during lunch so that she could prepare her child for the change as those two children sat in segregation for years and I anticipated that it would be even more difficult for that child to be segregated by herself. The mother told me that she never wanted her child to sit at the allergy free zone either and was going to talk to the school nurse to see if she could get her child removed from the peanut free table, her child has a mild allergy, not life threatening.

No words can adequately describe how much my child benefitted socially, emotionally and physically by removing him from being segregated from his peers at lunchtime. I regret that it took three years to change that arrangement and cannot imagine how much more he would have suffered if it continued if that arrangement continued on through the fifth grade.

I believe my action of removing my child from the allergy free zone during lunch resulted in a negative attitude/climate towards me from the school nurse and school principal (in January 2014 they banned serving food at classroom celebrations for the 3rd grade only, which I believe was in retaliation for me asking questions and raising concerns) which led me to email Region 14’s BoE to request that they form a district wide allergy management team to review policies and practices, which to date, I don’t believe a review of policies and practices has ever been done. Based on my experiences as serving as the parent representative on Region 14’s Wellness Committee, I don’t believe it will ever be done. The superintendent of schools, Dr. Anna Cutaia-Leonard, has refused to examine practices including transportation policies after repeated requests to do so.

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On October 19, 2015, I had a conference call meeting with John Frassinelli, Bureau Chief CSDE and Stephanie Knutson as I wanted to know why CT school districts are not following the CSDE's Guidelines for Managing Life Threatening Food Allergies in CT Schools as those guidelines state that an allergen free zone may be established and that not all students or families will need or want to use an allergen-free zone during the school day. (page 17) School options may include establishing allergen free zones, such as a child's individual classroom, allergen free lunch table(s) or areas in the cafeteria and food-free zones, such as libraries and music rooms, as well as enforcing relevant school policies, such as those that prohibit eating on the school buses. Individual student and family privacy needs and preferences should be considered in determining appropriate plans. Not all students or families will need or want to use an allergen-free zone during the school day.

Mr. Frassinelli stated that the CSDE puts forth many recommendations and guidelines, these are best practices and school districts are not required to follow them; local school districts have a lot of leeway to make their own policies based on what is best for that individual school district. They do not need to follow any guideline or best practice recommendation (as put forth by a panel of experts as in the case of the Guidelines for Managing LTFA in CT Schools) if they feel it does not suite their district's needs. A copy of an email to Mr. Frassinelli which recaps our conversation is below for your easy reference.

Based on my experiences with Region 14, school districts can pick and choose what guidelines and CT General Statutes they which to follow as there is no agency that has any authority over them other than the local school board which may or may not be responsive. Parents are left with no real recourse to implement change when school boards are unresponsive to their concerns.

Please recommend the passage of a law that prohibits any school district from the mandatory segregation of children during lunchtime based on an allergy and impose fines to any school district that doesn't comply. (Doesn't the CHRO prohibit segregating people based on a disability?)

Please recommend the passage of a law that requires school districts to perform regular evaluations for school nurses and to comply with public health code for hiring of school nurses and impose fines to any school district that doesn't comply.

Please recommend the passage of a law that details exactly what school districts must do in regards to transportation policies for children with life threatening allergies, such as notifying the bus company which students have LTA's and ensure a plan is in place in the event a reaction should occur and impose fines if the school district fails to comply.

Please recommend expanding the scope of the APA to audit policies and practices of each public school in CT to ensure compliance with CT General Statutes or create an agency that has some authority over public school districts. No parent should be burdened with the task of aligning their child's school district's policies with CT General Statutes or recommended best practices as members of the school district can be quite discourteous.

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Thank you for your consideration to these requests.

Sincerely,

Paula Paolino
Woodbury, CT

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Rachel Alagna, Parent

To The Connecticut State Task Force for Food Allergies:

My daughter has been denied safe access to Brookfield Public Schools in Connecticut since 2014. I am currently paying upwards of \$10,000 a year to send her to a private school that is able, without any significant impact to their budget, to accommodate a child with food allergies appropriately. As a single mother this is no small burden on me financially; however, I have been left with no choice other than to seek out an alternative to public school so that my daughter may safely receive an education.

My youngest child had a severe anaphylactic reaction to a bite of a peanut butter sandwich when she was two years old. Her pediatrician referred us to a pediatric allergist, who ran blood work and skin tests. The allergist explained in no uncertain terms that my daughter was to avoid all contact with peanuts and tree nuts. Anaphylaxis can affect different body systems depending upon the individual, the exposure, body temperature – any number of factors can come into play. But because her breathing was the earliest and most significant symptom by far, our allergist emphasized extreme caution as another reaction would likely follow suit and would only be more severe. When our pediatric allergist retired, we were referred to another group of allergists who specialized in food allergies. The diagnosis and opinions were the same, and we have had blood and skin tests run on two additional occasions with our current allergist.

In total, I have had approximately three meetings in person, six detailed letters, countless emails, and numerous phone calls with the Brookfield School District - regardless of my repeated requests for everything to be communicated in writing. The school declined all requests to record phone conversations or meetings. Even with several written explanations and documentation from my daughter's allergist and pediatrician, as well as peer-reviewed medical literature provided, the Brookfield public school system has been unwilling to accommodate my daughter's needs in any way other than to completely segregate her and highlight her as different from her peers. This would not only affect her psychosocial well-being, but would also set her up as a target for food allergy bullying in the future. The school also refused to provide home-bound tutoring for my daughter during the 504 process; our allergist stated unequivocally that it was not safe for my daughter to attend school until accommodations were put into place. Rather, this tutoring was dangled as a proverbial carrot,

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while the school worked with their district attorney to undermine any attempts for change in the policies I was seeking.

I was initially offered tutoring at our 504 eligibility meeting, so long as I signed a release allowing open verbal communication with my daughter's doctors and full access to all her medical records. When I retracted my permission, and explained that I wanted all communications between the school and allergist to be in writing and only medical records relevant to the situation to be released, the offer for the tutor was rescinded. Transparency was my reason for requesting everything in writing; however, the school clearly did not like the lack of legal flexibility that offered. I am alarmed that this desire to handle everything verbally, with no accountability for what is said, appears to be one of the many emerging trends of school districts in Connecticut when dealing with students who have food allergies.

Due to what my attorney informed me was an extremely dated district policy, I was unable to refuse verbal communication with my daughter's allergist without entering into litigation. I signed a different release, allowing a single conference call that I was to be present for, so that the school and the district physician could question and speak with our allergist. I was denied my request, through the school's district attorney to my attorney, to record the call. Tutoring was still being withheld at this point.

Our allergist spent over two hours on the phone in November of 2015 with the 504 team of the Brookfield School District and explained multiple times that food allergies differ depending upon the individual, even likening the variations in allergic children to the variations of those on the autistic spectrum. The school principal still has repeatedly brought up during meetings that other students in the school have food allergies with different medical recommendations, and that some of these students even have the same allergist as my daughter – citing this as the reason the accommodations requested by our allergist didn't need to be made. The demeanor in making this repeated statement was accusatory and condescending, certainly not professional in manner, and illustrating a disturbing level of willful ignorance.

Although I began this process in an attempt to make sure my daughter was not segregated from her peers, by the time we had our final meeting all I was seeking was a nut-restricted classroom and staff trained to recognize anaphylaxis and administer epinephrine available to my daughter at all times (classroom, lunchroom, recess, specials, bus). The school was much more concerned that enforcing a nut-restricted classroom would make the other children feel as though they were being "punished" than they were with the safety and wellbeing of allergic children. They also denied my request to have the staff trained or have my daughter's epinephrine accessible to her throughout the day. Epinephrine in a locked cabinet in the nurse's office, with only the school nurse available to administer, is not a reasonable accommodation for a child with a life-threatening food allergy – particularly when they are being put into a situation where the exposure to their allergen is so significant.

The only way the school was willing to allow my daughter's epinephrine to be present in her classroom or on her person, was if I signed a release allowing my six year old to self-administer,

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thereby relieving the school of all legal responsibility to do so. Not only was I personally against this, our allergist had already vehemently explained to the school that adults are at times incapable of self-administering epinephrine during anaphylaxis; she had counseled all members of the 504 team present that the body systems affected could cause a loss of consciousness or disorientation, and explained that a six year old child certainly shouldn't be expected to use an auto-injector on herself.

Even after the lengthy phone call and thorough explanation from the allergist, the principal of Center Elementary School expressed that she still did not believe my daughter needed epinephrine available in her classroom and that she did not believe the allergist in any way implied that this would be necessary. I explained that since my request to record the phone conversation had been denied, I would be happy to have the allergist write yet another letter, briefly stating exactly that. I was told that this would be sufficient to sway the 504 team's stance on the matter and initiate a change in board policy for the location and administration policy of the epinephrine. However, upon receiving the letter, Dr. Charles Manos of the special education department called with the principal of Center School on the line, to state that the district would require my daughter to be evaluated by an allergist of their choosing in order to allow her medication to be present in her classroom. I offered to get a second opinion, or to pick from a list of district approved allergists. My offer was rejected and I was told that only the allergist specifically chosen by the school would suffice for this secondary evaluation. I expressed severe distrust at the motives behind such a specific request for this evaluation. At this point, tutoring was again dangled in an effort to obtain my compliance. This is another example of what is becoming commonplace in the state of Connecticut; school districts are willing to spend money on their own specific medical specialists to counteract the advice of the specialists who have been treating these allergic children.

After the school's request for this evaluation, my lawyer informed me that the only option at this point was to enter litigation. He said that chances were about 50% as far as which way the case would go. As my legal funds were dwindling quickly, I couldn't continue to fight for my daughter's right to attend Center Elementary School any longer. I pulled out of the 504 deliberations and withdrew her enrollment from the Brookfield Public School System. This is another terribly disturbing trend I've noted in Connecticut schools dealing with accommodations for allergic children; parents have little recourse unless they have unending financial resources and as such, schools are pushing parents into litigation in order to avoid granting the accommodations requested by board certified allergists.

Young children, particularly elementary aged and younger, have no one to advocate for them on a daily basis if there are nuts in the classroom. This is the only point in their lives that they will be forced to be in such close contact with their allergens, which are life-threatening, with no recourse if something makes them scared or uncomfortable. Any other situation – restaurants, fairs, stores – these children have the option of removing themselves from exposure or from a potentially unsafe situation. But not at school, which they are required by law to attend – and they are entitled to that education without having to put their lives in jeopardy, just like any other child. How well can a child learn in a situation where they are navigating such an extreme but invisible medical condition, with a lack of support from the

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school and administration, and without immediate access the life-saving medication they typically carry on their person? And then for children entering into middle school and beyond, where peer pressure and the desire to blend in with the crowd come into play – how are these children able to focus on education when social pressures and food allergy management are occupying so much of their limited, albeit developmentally appropriate, self-management skills. Their medical condition should not be exposed by way of segregation to the entire student body; this social stigma only increases the likelihood of food allergy bullying for these children once they are older. The education of the teachers, board of education, school professionals, bus drivers, aides, nurses, and the entire student/parent body is of the utmost importance. There must be a safe and inclusive way for schools to manage these disabilities.

I know that there is, because my daughter attends such a school – in the very same state in which public schools refused to accommodate her. Currently, the school my daughter attends has a ‘no nut’ policy. They enforce this by way of supplying alternative foods for students if a parent accidentally sends in an item with nuts. The food containing nuts is sent back home with a note reminding the parents of the food policy – although this is rarely necessary. Celebrations in the school are food-free; the students focus more on the occasion and camaraderie than what is on the table. I have never heard a complaint voiced. This lack of complaint is likely due to the education of the school staff, which filters down through the parents, and in turn that same education, understanding, and acceptance reaches the children. Parents provide snacks for the elementary aged classrooms. Only fresh fruits or veggies may be sent in and the school supplies hummus, salsa, etc. My daughter has epinephrine in the nurse’s office and in her classroom. Her teachers are trained in recognizing the signs of anaphylaxis and administering epinephrine. There is a no food-sharing policy throughout the school, and my daughter is free to sit with whomever she likes during lunch and snack – the same as the rest of her peers. In a culture so attached to food, my daughter’s current school illustrates that a child’s life, education, and emotional wellbeing is worth far more the importance of any particular item of food.

I know that I am not the only parent being met with disdain and contempt upon trying to acquire accommodations for a child with food allergies in Connecticut. This letter was incredibly taxing for me to write and if communications from parents are lacking, I can tell you that it is not for a want of change or due to a small percentage of the population being affected. It is because of the immense amount of energy, emotion, and time that has already been put toward these battles for our children’s rights to an education. I can only hope that the Task Force is able to generate policies across the board for the state of Connecticut, so that these children have access to public education without putting their lives or emotional health in jeopardy.

Thank You for your time in reviewing my testimony.
Sincerely,
Rachel Alagna

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Robin Comey, Parent, Branford

To the members of the Task Force -

As a parent of a child with life threatening food allergies and an advocate and member of Food Allergy Education Network I have a perspective that could be of help to the work you are doing. I will try to make this brief but poignant.

As a parent, I have witnessed first hand the hard work we did as a small group of engaged parents advocating for creating consistent policies and procedures to keep our children safe and included in schools. I will share what I think has worked and what improvements could be made.

What we know works:

- * Classrooms are learning environments and should remain free of celebrations that include food. Local school board policies should reflect as such. No exceptions.
- * Children with food allergies should be identified by administration and provided the opportunity to be protected by a 504 plan.
- * Best practices must be consistent in each district, school to school. Classroom signage and other best practices in place should not be left up to building by building decisions.
- * Good policy and practice is very helpful in elementary schools while children are developing an understanding of their food allergies and where the numbers of children with food allergies are the highest.
- * No food should be used as rewards. There is no place for it in schools.

Improvements can be made in the following areas:

- * We need to improve communications and follow through of regulations.
- * Education of all staff must be improved to build understanding of the unique challenges that food allergy children experience, both emotionally and in what they do each day to keep themselves safe
- * Policy should be wrapped into a overall wellness policy and sub committees on a local level are helpful only if there is a complete understanding of the task at hand.
- * Intermediate schools and beyond are the wild wild west. Teachers are sending messages to children that are not helpful. They are giving out food and hiding it from administration, as well as telling the children not to tell their parents they are still using food or candy as a reward
- * PTA's and PTO's should be encouraged to work cooperatively with food allergy families, such as having a representative on all events that allow food, so that ALL children can be safe AND included. School leadership (principals and the like) should be respectful and not take a side one way or the other.
- * Once policy and regulations are made, regular yearly or bi-yearly reviews of said policy and best practices should be done.

As a member of Food Allergy Education Network I had a recent conversation with a school nurse from a regional school district in the state who seemed not only annoyed with what parents were requesting for their food allergic child, (a safe snack list) but also she was insensitive, dismissive and judgmental. This is certainly not acceptable. When I suggested that policy at a district level should be developed and classrooms were for learning and birthday

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celebrations were unnecessary, her incredulousness was palatable. It was clear she had preconceived notions of what kept children safe and that food wasn't the problem, the parents/child was the problem.

I will close with another short personal story which shows what happens when parents advocate, even in an environment where policy is in place.

Someone in close proximity to my child's elementary school was feeding the squirrels by placing piles of peanuts within 2 feet of the playground fence so it was brought to the attention of the school principal. The parents requested attention to this safety matter and requested additional signage to bring it to the attention of the person feeding the squirrels. After several emails back and forth, over a series of days, administration minimized our concerns, pushed back, denied responsibility for the property and even placed blame on the animals. FINALLY, they put up signs and the people stopped feeding the squirrels peanuts. Great right? Why should we complain about that? Well we didn't complain, we thanked them for doing what we had requested and moved on. HOWEVER, the problem as we saw it, was the 3 signs that were put up were SO large and overkill in number, as well as permanent. It message to the parents and children was to embarrass the parents and clearly a retaliatory move from one administrator. This is just one example of what happens when schools don't have a clear understanding of food allergies, have no respect for parents and are left to figure out how to troubleshoot a problem on a school-by-school basis.

Thank you for your attention to this important growing health crisis. I look forward to your recommendations.

Robin Comey
Branford

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Rosemary Szot, Parent

Hello Task Force,

My name is Rosemary Szot, and I am the parent who spearheaded legislation, introduced by my legislator Dimetrios Giannaros, which became PA 05-104. I began this journey when my son was in Kindergarten, and there were no state guidelines, and certainly no school policies. It was not an easy journey. I am listed in the acknowledgements of the original 2006 guidelines. I was also the co-event planner of the Food Allergy in Schools Summit, 2006, where the original guidelines were rolled out. My comments on the original guidelines are simply to let you know that I was only one voice, of many on the committee, and there were many heated debates, especially surrounding promotion of 504 plans, peanut bans and bussing. In the end, mostly due to budget constraints and timelines, the guidelines were published, but were not perfect, and did not include everything I had hoped for, BUT, I was extremely proud of the accomplishment. My son is now a senior in High School, and our next hurdle will be selecting a college that can accommodate his disability. I ask the committee to not end the discussion at grade twelve, but

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to expand what I started, and to continue to support our youth as they step out of High School and continue on their educational journey.

Thank you,

Rosemary Szot

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Shannon Martinello, MD, FAAP

I am writing as a mother, pediatrician and school medical advisor. I am astounded by the State of CT lack of understanding of best practice in regard to epinephrine usage for life threatening allergic reactions. First, I cannot understand why glycogen storage diseases are at all linked to this issue, the two are unrelated illnesses, but that is a topic for another time. Second, to have any option for a family to opt out of a lifesaving medication for a known or previously unknown allergen is, to me, negligent and ridiculous. It would be on the level of allowing families to opt out of the Heimlich maneuver if their child was choking, or to opt out of using an AED/defibrillator if the child suffered a cardiac event during gym class. It is negligent, pure and simple. Families may not fully understand the ramifications of what they are opting out of. School districts nationwide are being sued (rightfully so!) for lack of timely administration of this medication. It goes against all legal and moral obligations that our school nurses and medical personnel are held to perform. It is directly against the licensing of our school nurses/physicians to knowingly withhold this medication. Public arenas are seeking to have epinephrine available as a life-saving medical option in the same way that AED/Defibrillators are available. Unless a child has a very specific DNR (Do Not Resuscitate) order that specifically dictates that personnel are not allowed to use epinephrine, any and all children/people should have access to this potentially life-saving medication.

Thank you.

I would be happy to discuss this further and offer any other clarification that you'd need in revisiting this issue to keep our children safe at school.

Shannon Martinello, MD, FAAP

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Suzanne DeLuca and Lew, Parents

To the Food Allergy Task Force

As parents of a child with food allergies, we are always vigilant with food safety measures and advocate accordingly. We have had luck as our child's bus driver is epi-pen trained and a few local restaurants have made food allergy accommodations.

A challenge we still face is that even though the board policy indicates no food in the classroom, there have been instances when a teacher asks room parents about food at a classroom event. It's frustrating and emotionally draining to have to remind the teacher that no food in the classroom means no food in the classroom. The issue has always been resolved which we appreciate, but there is no need for it to exist if policy is followed. Overall, we are pleased with the school and our child feels safe and happy at school which matters a great deal to us. Enforcing policy and accountability are issues that many food allergy parents still experience and we hope the Task Force can help resolve and alleviate.

Thank you,

Suzanne and Lew

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Vicki Earl, Parent

Dear Madison Board of Education members,

I am writing to you on behalf of my son, Nicholas Earl, who has a life threatening food allergy with a high likeliness of anaphylaxis as well as other children in our school system with similar conditions. Attached is a letter from his allergist.

Nicholas is currently a fourth grader at Ryerson who is highly allergic to peanuts and tree nuts so the school bus ride continues to be a safety concern. Unlike some other food allergies, when a person reacts with a nut allergy, minutes can literally mean the difference between life and death. In March of 2015, I contacted Superintendent Tom Scarice with a request to have Madison school bus drivers trained to administer Epipens. At that time, I was referred to Art Sickle who advised me "Madison Public Schools has not required bus drivers to be responsible for administering medication of any kind." Mr. Sickle also mentioned that if a student had a 504 plan or an IEP which specifies that an aide must be present on the bus to potentially administer medication, the District would provide that person and see to their training, rather than the bus company. At that point, we taught Nicholas how to self administer his Epipen and had him carry it in his backpack. Nicholas was also well educated that this should never be removed from his backpack unless he needed to administer it to himself.

Nicholas was personally faced with a potentially dangerous situation on the school bus on June 16th. A seemingly well-meaning child offered my son an Oreo which he typically can have. Nicholas noticed that the Oreo looked "different" and told the child he could not have it

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because it could contain nuts and he was very allergic. The child said it was a peanut butter Oreo and then ate it when Nicholas declined. Nicholas went on to explain that he was so allergic that he could not even have this child touch him after touching peanut butter. The child then challenged my son and asked if he could “try touching him” to see what would happen. I was informed of the incident by Kelly Spooner and the school addressed this with the parent of the other child. The day after this incident, the bus driver had not been made aware of any incident until I informed him. At this point, I again requested through Mr. Sickle that my request for Epipens on school buses to be the standard for all children be reconsidered. In addition, I requested if this request would not be considered, then I wanted my son’s bus driver in the fall be trained on how and when to administer an Epipen. I offered to provide the bus driver with the Epipen for them to carry while my child is in their care. I was told my request would be considered over the summer.

In August, I was referred to Liz Battaglia to assist us in creating a 504 Plan for Nicholas. On October 14th we met with the principal, school nurse, school psychologist and his teacher to review the 504 plan request. Once the plan was in place, I requested an “accommodation” for Nicholas as it states is his right under a 504, to have his bus driver or adult designate be Epipen trained. I again offered to provide an Epipen to the bus driver and assist in training. This request was denied as it is not part of the current policy.

On October 21st I learned from my older son Andrew Earl, who is a sixth grader at Brown, that a child on another bus had an allergic reaction on the way to school. According to that child’s parent, the child had to wait more than 20 minutes before having medication available and she was fortunate that she only ingested one of her milder nut allergies. Andrew’s bus waited at Ryerson while waiting for the bus with the medical emergency to arrive at Brown. I am told that students were discussing how the bus driver having the medical emergency had to “floor-it” to the school bypassing other stops in an effort to get this child medical attention. Thankfully the child was ok however, how many other children were potentially at risk during this avoidable incident? I again, reached out to Mr. Sickle to & Liz Battaglia to request this policy be changed before a tragedy occurs.

On October 22nd I contacted the bus company directly and spoke to Magda Grayson and mentioned my request about bus drivers carrying Epipens. When I mentioned the incident that had occurred with the student at Brown she abruptly said “that child should have had been carrying their own Epipen” her lack of empathy or concern for this child and mine was insulting to say the least.

In November, Nicholas was approached on the bus again by the same child who offered him the cookies last spring. This time, the child was offering him a Snickers candy (contains peanuts). I notified Kelly Spooner and she addressed the issue with the other child. It is my understanding that this child was removed from the bus for a few days and now rides the bus with an adult supervisor. It is appalling to me that Durham School Services provides an adult to babysit a child with behavior problems but will not provide an adult for my child to address a potential life threatening situation.

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I have been repeatedly reminded of the “no food on the bus policy” which provides no comfort as it is a policy that is 1) not enforced and 2) my child tends to have a delayed reaction and doesn’t need to be eating something on the bus to be concerned that there is a risk of anaphylaxis. I do not believe there was food ingested on the bus incident that occurred October 21st but cannot be certain.

I am available to discuss this further with any or all members of the Board. Thank you for your consideration of requiring bus drivers to be trained to administer EpiPens and your commitment to keeping our children safe during all aspects of the school day.

Sincerely,
Vicki Earl

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Patricia Donovan, Parent

December 28, 2016

Dear Members of the Task Force To Study Life-Threatening Food Allergies in Schools (CT):

I am writing to you as not only a parent who has 17 years experience in managing school age children with multiple life-threatening food allergies (peanut, tree nut, dairy, eggs plus asthma and oral food allergies), but as one of the parents who brought this legislation forward, testified before the Education Committee, has advocated for all students with LTFA at the local school level, has attended food allergy conferences, has become certified in health and nutrition to support the nutritional and immunity needs of this subset and has attended almost every one of your task force meetings.

Witnessing this process has been almost a complete reflection of the process that took place in 2014 in my local school district, Fairfield, CT, to update its 8 year out of compliance BOE policy on Food Allergies. While you have gathered regularly for 4 months and garnered expert testimony and research in an attempt to fully understand this issue, this same process took over 1 year at the local level but DID NOT include expert testimony or MEDICAL advice. In fact, in several instances, it was parents who had to hire a lawyer to bring to the policy meetings to explain the school district's obligation to students under CHILD FIND. It should not ever take a school district BOE policy committee one year to create a policy that protects the health, safety and inclusion of students. Additionally, lay people without medical advice should never be debating or hashing out which protocols are necessary or not to keep students with a medical condition safe. While parents, teachers, administrators are allowed to comment at local BOE policy meetings, it is only after the debate between members has taken place (many times over false or inaccurate information) and does not have to be considered. It is vitally important that you understand how your work on this task force is greatly overdue and how much your work

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can help local districts serve their students and communities better. Yet this will only be possible through a complete rewrite of the current Guidelines, better legislation and very clear language.

I must stress how dangerous and volatile this situation can become for parents who advocate for their students with LTFA in their own district. In Fairfield the new policy was met with intense community backlash from parents who did not want to change their students' snack, from teachers who complained about the amount of time it would take to wash hands, from the Teacher Union rep from CEA threatening a contract renegotiation, from our teachers mocking label reading protocols out loud, to PTA leaders calling on parents to unite against food allergy protocols. This should never happen to any parent trying to safeguard their child's health in school. The lack of clear guidance from the State Guidelines, the CSDE (who was contacted on several occasions by BOE member, parents, local legislator) and the lack of local medical advice led to the public debate of health protocols based on community convenience, the demonization of parents asking for compassion and understanding and left children with food allergies feeling unsupported, isolated and burdensome to their teachers and peers. I have never known any other policy related to a health condition to be openly debated like this before. Further, after the policy was unanimously approved by the BOE (and I must give kudos to them for persevering), our deputy superintendent convened a secret district wide allergy committee to discuss how to implement the new policy (no meetings were publicly noticed, no member list posted, no minutes available). The resulting administrative regulations completely undermine the Board policy and negate the protocols most needed: it calls for using hand sanitizer to "wash hands" after eating which research has shown is NOT effective for allergen removal and is specifically mentioned as ineffective in the guidelines, and students who bring nuts into nut-free classes will be allowed to eat their snack at their desk, non-compliant snacks will not be swapped out. This is simply unacceptable and does not in any way reflect best practices.

New Guidelines must treat LTFA as the medical condition it is and mandate safety and inclusion protocols that are medically based best-practices and that reflect the continuity of care that we parents exercise at home and outside under our own care. We do not isolate our children at home by making them eat at a separate table, nor do we engage in food-based activities that would compromise their health and tell them to sit to the side and watch.

ACCESS: Our children are required by law to attend school and schools must learn to be flexible in order to integrate our students as fully participating members- it is not acceptable that our students do not have access to emergency medicine for before or after school activities, or on school transportation, and therefore lack access to these activities. School based activities are an extension of the school day and must be accessible by all students, regardless of disability. Please remember that the more assets a student has - the feeling of being understood and supported in their environment, the number of [people they have access to, the number of activities they can participate in, etc- the better their long term outcome and reduction in risky behavior.

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Students with life-threatening food allergies lack equal access to the school food program. In my school district we do not have an interactive school lunch menu which would allow instant access to nutritional and allergen information allowing my students to safely access lunch. My children have never been able to eat lunch from school (15 years). In order to get the information, I would have to call or visit central office to see the food labels, possibly call manufacturers to ascertain cross contamination risk and then double check at my local school to ensure they were even using the same product listed as substitutions happen all the time.

Students with LTFA do not have equal access to their educational environment, especially their classroom. The prevalence of food in the school day has overtaken school culture. On any given day you will run into parents bringing food to share in the classroom: green bagels on St. Patrick's Day, cupcakes for birthdays, candy for Valentine's Day, etc. Often times when snack restrictions are proposed, there is outrage from parents that their child will only eat one thing, or that they are missing teeth therefore can't eat fruit, etc. Food restrictions need to be proposed for the overall health of all children, not just for food allergies -- obesity, diabetes, ADHD, autism, etc. Snacks are not meals and should never replace or interfere with meals in the school day. Celebrations can be well celebrated through play, and creative activities. Unsafe foods in the classroom cause issues of prompt and proper cleaning and isolation of the allergic student in their classroom, their learning environment. When I remember my elementary school experience I do not remember any school food celebrations but I am marked by favorite books, caring teachers and distinct memories of being introduced by my kindergarten teacher to the art of Modigliani and Chagall, and the songs we sang in music. Schools need to re-value the educational experience and creativity over food to make kids feel good.

FAPE (Free and Appropriate Education): Further, the wishy washy language of the Guidelines translates not only into the development of poor BOE policies but also into weak 504 plans. As safety protocols are listed in the guidelines as "to be considered", school districts very often say, "we've considered that protocol" and we are not doing it. As an advocate and witness I have sat in 504 meetings and have been shocked by the willingness of school administrators to go against a doctor's orders or to hire their own doctor to simply negate the student's Board Certified, life long specialist. There is no discussion on the part of the teachers or nurses in many cases even though they have the most contact and knowledge of the student concerned. They very often sit silently, seemingly afraid to talk. Guidance and training of school administrators on safety protocols and FAPE are much needed from the CSDE. School budgets spent on legal fees are skyrocketing and deprive LEAs of scarce educational funds. In my district alone, legal fees used to be budgeted at \$300K for a 10,000 student district. Today we are spending between \$800-\$1MM. I know for certain that some of these funds are being spent on lawyers and outside doctors to fight food allergy protocols that are best practice and would cost less to implement.

EDUCATION: Another imperative that has not gotten enough attention is the need for education for all on food allergies.

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- 1) Peer education at the earliest ages in school would help create an accepting and supportive environment and relieve parents of the burden of constantly advocating and/or coming into classrooms on their own to educate students and staff. This poses several issues: information may not be developmentally appropriate, it will not be standardized, and it forces parents to divulge medical information by being in their student's class and makes the student embarrassed. While at lunch in middle school my youngest child was asked by his friend, "I just don't understand why you haven't died yet?" because he knows my son is allergic to a lot and he himself doesn't understand what is in foods or how to identify allergens.
- 2) Staff education will safeguard students and bring much needed awareness to social-emotional needs. Yes, our children talk about dying and are aware of their mortality which may shock most adults about our children. Our children must understand that a simple mistake can have serious consequences, they need to feel safe with adults in their schools and trust their concerns will be taken seriously.
- 3) Education through the Health curriculum will go a long way to safeguarding food allergic students as they grow into independence and self-care. Middle schoolers and high school students spend significant time away from home and from their parents. As parents we must educate our children to always carry their medicine and to always follow their safety protocols but peer awareness and acceptance can help de-stigmatize children carrying their epinephrine injectors and de-stigmatize lack of participation in certain food-based activities and hopefully promote more inclusive activities. Additionally, if a student has an allergic reaction, their peers would recognize the symptoms and be able to administer and get help. Much like CPR has been added to the Health curriculum standards, allergy awareness and epinephrine administration can be taught.
- 4) Community based education and services: currently the Department of Health has little to no information on food allergies on its public website. Despite prevalence rates increasing without slowing, 1 in 13 children, and no cure available, this public health epidemic goes unaddressed. Community based education is needed to increase the knowledge of allergic syndromes, it's complications with asthma and eczema, it's relationship to feeding young children safely and nutritionally, and responding to emergencies safely and in a timely manner. How are daycare and pre-schools prepared to accept and safeguard these children? How can community children participate fully in Parks and Recs programs without education of staff and coaches? Starting early with community based education would fully support transition to our schools. The Massachusetts Department of Public Health does a great job of providing education, information and data around food allergies and related health conditions.

In conclusion, I ask that this task force not conclude the way my district did, by undoing all of its good work by being afraid to ruffle feathers and afraid to require accountability. As parents we want to partner with our schools and we want all children to thrive and learn to be empathetic, compassionate human beings and as adults we should model this. I ask that you use strong, clear language in your recommendations which will help all school districts to safeguard and include our students. Local districts do not have the resources of endless legal and medical advice and should not be deciding safety protocols for themselves. Education and training must

APPENDIX C

be provided to districts, free of charge, from the DPH and the CSDE, so that it is standardized, appropriate and medically sound (I believe this has already been mandated by Statute 10-212 (a) Sect. 2 but has yet to come to fruition).

I thank you all for your time and effort on this Task Force on behalf of our children.

Sincerely,

Patricia Donovan
Fairfield (Southport), CT