

From: Gina Lee

Sent: Thursday, December 08, 2016 1:04 PM

To: Navarrete, Leslie

Subject: Public Comment for the Task Force to Study Life-Threatening Food Allergies in Schools

## 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 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?

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

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.

(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 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 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 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 Menett 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-One-Page.pdf>

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

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