

From: Paula Paolino [mailto:paolinopaula@gmail.com]
Sent: Tuesday, October 04, 2016 2:12 PM
To: Phillips, Jeanie
Subject: Fwd: 10/19/15 Conference call follow up

Please forward this information to the Task Force to Study Life Threatening Food Allergies
Please acknowledge receiving this information.

October 4, 2016

Erin Spaulding, Parent, Co-Chair
Dr. James Rosen, Allergy Specialist
Michael Corjulo, School nurse supervisor
Salvator Urso, Principal, McGee Middle School
Patricia Shoemaker, Food service director
Jessica Curran, Parent
Regina Owusu
John Frassinelli, CSDE

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 lunch time. I could not locate any information on the website in regards to cafeteria seating arrangements.

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.

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.

Thank you for your consideration to these requests.

Sincerely,
Paula Paolino

Woodbury, CT

----- Forwarded message -----

From: **Paula Paolino** <paolinopaula@gmail.com>

Date: Mon, Oct 19, 2015 at 6:27 PM

Subject: 10/19/15 Conference call follow up

To: "Knutson, Stephanie" <Stephanie.Knutson@ct.gov>, john.frassinelli@ct.gov

Mr. John Frassinelli, Bureau Chief, CSDE

Ms. Stephanie Knutson, Education Consultant, CSDE

Dear Mr. Frassinelli and Ms. Knutson,

Thank you for taking the time today to discuss my concerns with:

- school nurse evaluations
- professional development requirements for school nurses
- mandatory segregation of students with allergies during school lunch among some CT school districts.

The information you shared with me was useful and I have prepared a summary based on our conversation. Please let me know if any of the information below is inaccurate and please send me any comments or edits as you feel necessary.

Ms. Knutson stated that school nurses are required to have 10 hours of professional development every two years. Is that a recommended best practice and school districts have the option as to whether they want to follow that recommendation or is it an actual requirement that has to be fulfilled? Please send me any information you have pertaining to professional development requirements for school nurses.

Based on our conversation, it is my understanding that the process of regular performance evaluations for Connecticut school nurses is not a requirement but falls under the best practice category and local school districts can determine the frequency of occurrence.

We discussed the CSDE's Guidelines for Managing Life Threatening Food Allergies and cafeteria seating arrangements for children with life threatening food allergies and although the guidelines state "School options may include establishing allergen free zones, allergen free lunch tables... 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" school districts have the discretion to implement a policy that makes it mandatory for children to sit at an allergy free zone, even if the parent does not want that type of accommodation for their child.

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 in the case of the Guidelines for Managing LTFA in CT Schools) if they feel it does not suit their district's needs.

In summary, even though C.G.S. 10-212c required the CSDE to develop guidelines for the management of students with life threatening food allergies and each local and regional board of education shall implement a plan based on these guidelines, these guidelines serve as recommended best practices and each CT school district has the leeway to determine which practice, if any, they choose to implement for their district. If a parent has any concerns with their school district's policy, the burden is on them to approach the BoE and ask them to change their policies to align with the recommended practice.

Since the CSDE has no jurisdiction over school districts policies, it seems the only way to prevent the mandatory segregation of children during their school lunch is to seek the assistance of state legislatures to introduce a public act. Not sure I will have any success but if Texas was successful in passing a law that prevented school districts from banning cupcakes from being served for their children's birthdays, I may as well see where I can get with this initiative.

Again, thank you for your time and please let me know if any of the information as noted above does not accurately reflect the information shared in our conversation earlier today. You have been a valuable resource for information and it is greatly appreciated.

Sincerely,
Paula Paolino