

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 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.

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.

- 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 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