

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, 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, 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 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