

**Subject:** written comments regarding transportation issues to the Task Force To Study Life Threatening Food Allergies in Schools

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 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 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 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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