

March 10, 2015

Dear Education Committee Members:

I am writing to you in support of HB6975: An Act Establishing a Task Force to Study Life Threatening Food Allergies in Schools.

The issue of life threatening food allergies in schools is one that is incredibly personal to me. Both of my 9 year old twin boys have anaphylactic allergies to peanuts and tree nuts and they attend Ct public schools.

Food allergy prevalence in school aged children continues to rise at epidemic rates. Connecticut is right on trend with an average of 1.5 students per classroom having a confirmed diagnosis of life threatening food allergy.

At present there is no cure or approved treatment of life threatening food allergies. There are only two elements to the prescribed medical protocol for management and treatment of life threatening food allergies – strict avoidance of allergens across all environments and prompt administration of emergency medication to mitigate the allergic response and buy time until further life saving medical treatment can be administered.

Despite state and federal guidelines, the ADA and Section 504 of Rehabilitation Act of 1973, there still remain multiple and significant barriers to safety and inclusion for students with life threatening food allergies in CT. The disparity in policies and implementation from district to district, building to building, and at times, from classroom to classroom is staggering, and provides a clear indication that many districts :

- 1) do not fully understand the issue of managing life threatening food allergies in school and their legal obligations to provide safe and equal access to education for students with this chronic medical condition
- 2) do not know how to operationalize either the state or CDC guidelines on the management of life threatening food allergies in schools
- 3) continue to rely all too heavily on emergency response policies and protocols because they are either unwilling or unable to implement recommended best

practices for the prevention of exposure to life threatening allergens due to public opinion or special interest groups.

- 4) will provide safety but often at the cost of inclusion, and vice versa.

With that in mind, I ask that the committee seriously consider whether students with life threatening food allergies are being provided with equal access to and benefit from Connecticut's education system.

In late 2014 the National Association of School Boards of Education released four state specific Anaphylaxis Policy Handbooks meant to facilitate improvements to existing state policy and guidelines, with the goal of strengthening implementation to keep school children safe. Connecticut is one of the four states they directed their efforts towards, due to the obvious gaps that need to be addressed. One of the most significant deficits the CT handbook points to is the lack of a comprehensive, state-wide reporting system to capture and analyze anaphylaxis related data, which can and should help inform state and district policy, as well as the implementation of consistent standards of care.

When it comes to life threatening food allergies "Child Find" seems a foreign concept, as illustrated by the low reporting of 504 accommodation plans for students with life threatening food allergies, despite being classified as a disability. Yet the CT DOH reports that both Emergency Care Plan development and calls to 911 have been on a steady incline in the past 10 years, again indicating that schools are overly reliant on emergency response protocols. Managing life threatening food allergies requires constant, proactive intervention. Emergency response will always remain a critical component to managing life threatening food allergies. However, once we have reached the point that a child is experiencing anaphylaxis and emergency response is activated, it is often because the child was not adequately protected or supported in school. We must make greater efforts to protect students from experiencing allergic reaction events, as they are not only life threatening, they are life changing.

All too often, our schools are failing to provide the safeguards that must be in place to keep our students with life threatening allergies safe and included in their learning environments. The burden often falls to the student to self-manage their condition and navigate the complex, landmine ridden school environment, which can and does have a tremendous impact on their ability to be both students and children. The burden also often falls on the parents of students with life threatening allergies to not only advocate for their child, but to educate school staff, administrators, their child's peers and their parents, and as in my own case, our district Boards of Education. Parents who work vigilantly, to help keep their children safe and healthy in all environments are often met with skepticism, false promises, and hostility.

They are often required to go above and beyond reasonable efforts to ensure accommodations are made for their child with this invisible, yet confirmed, medical disability.

In the aggregate, this issue points to a lack of oversight, accountability and enforcement that leaves our children at significant daily risk and undermines the benefit of their education. These issues warrant investigation and with that, I respectfully request that the committee move this bill forward.

Thank you.

Jessica Curran

Fairfield