

3/10/2025

Re: Testimony in Support of H 5491 Health and Safety of Pupils amendment "Seizure Safe Schools"

Dear Chair McNamara and members of the House Education Committee:

I am Clare Tyler from District 19, Cranston.

I support H 5491, the Seizure Safe Schools Act. The Seizure Safe Schools Act would allow school professionals to be trained to respond to seizures and give rescue medications to kids who are actively having seizures. It would also provide age appropriate education on epilepsy for all kids.

I was diagnosed with epilepsy when I was 20 months old. I have a rare genetic disorder called PCDH19 epilepsy. I went to public schools through the fourth grade, and because my mom had the time, resources and knowledge to advocate for me, which not all parents have the privilege of, one person knew how to administer my medication in case I had a seizure: the school nurse. However, the school nurse was rarely on site. If I had a seizure in school when the nurse was not around, no one would've known what to do. No one would have administered my rescue medication, which would stop the cluster of seizures, a process where multiple seizures occur in a short amount of time. They would wait and call an ambulance. Not only would this have delayed the administration of my rescue medication, which can usually stop the seizures on its own, but it would have resulted in the unnecessary cost of an ambulance ride and hospital admission. For low-income children, this unnecessary cost would be particularly harmful.

Right now, only a school nurse can administer emergency seizure medication to stop a child's seizure. If the nurse is not on-site (which is often the case), then the only other option is to call 911, which uses up precious time, takes longer to stop the seizures, and is costly. Other school personnel can be trained to administer the emergency medication to avoid the costs of an ambulance.

Not having options for others to administer emergency medication can mean that children with epilepsy cannot fully participate in school activities (such as field trips). Like other children with disabilities, children with epilepsy deserve to fully participate in all school activities.

This bill is also important to me because of the clause stating all kids in all schools should receive an age-appropriate education about epilepsy. This part of the bill is critical. Children and school personnel who are uneducated sometimes make jokes that are hurtful to people with epilepsy. I heard epilepsy jokes in almost all the schools I went to, both public and private. Even a teacher in high school was in on an epilepsy joke and asked anyone in the class if they had epilepsy, so I raised my hand, and the class went quiet. Seizure education is critical for both teachers and students to reduce stigma and social isolation among students with epilepsy.

I urge you to vote for H 5491.

Thank you for your time and the opportunity to write in favor of bill 5491.

Sincerely,
Clare Tyler

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District 19