

Lisa Cataldi

From: Danielle V <danielleandkurtis@gmail.com>
Sent: Monday, March 31, 2025 8:28 PM
To: Rep. McNamara, Joseph M.; Rep. Noret, Thomas E.; Rep. Kislak, Rebecca M.; Rep. Biah, Nathan W.; Rep. Casimiro, Julie A.; Rep. Cotter, Megan L.; Rep. Donovan, Susan R; Rep. Fascia, Richard R.; Rep. Giraldo, Joshua J.; Rep. Perez, Ramon A.; Rep. Phillips, Robert D.; Rep. Read, III, Earl A.; Rep. Roberts, Sherry; Rep. Shallcross Smith, Mary Ann; Rep. Voas, Brandon T.; House Education Committee
Subject: Regarding H5491

Dearest Committee Members,

I write to you urgently requesting your full support of House Bill H5491, the "Seizure Safe Schools Act". As you already know, this bill creates safer and more supportive school environments for all Rhode Island students with seizure disorders. As a mother to a five year old with uncontrolled epilepsy, I have been following this bill closely. Please allow me a to express why it is imperative we pass this legislation.

My son attends an inclusive preschool program in Westerly, RI where he receives a free and appropriate public education for a total of ten hours per week. He has an emergency care plan created between his neurologist and the school nurse to administer Diastat when he has a seizure lasting over three minutes. During a prolonged seizure, my son's life is in jeopardy- he will stop breathing, turn blue, and sometimes his pulse drops to dangerously low rates. When a seizure occurs, acting fast to intervene with medicine can mean the difference between life and death. This is not a matter I take lightly.

When I send my son to school, all of the responsibility falls on to the school nurse. As it stands now, only the nurse can administer life saving medication to my son during a seizure. The plan is simple enough -when he has a seizure at school, the teacher calls the nurse to comes to assess him, and at the three minute mark the nurse will give him rectal Diastat and immediately call 9-1-1. If emergency medication is not given within the timeframe, status epilepticus occurs causing brain damage from oxygen deprivation, and the can lead to cardiac arrest. Prolonged seizures can be fatal. School nurses are in high demand, and there is a critical shortage. On average there are over 600 students to one school nurse in Rhode Island. Epilepsy affects 1 in 26 people, and 1,300 children live with epilepsy in our state. My son is one of them. There are many students in school who have a seizure disorder, based on those statistics provided by the epilepsy foundation of New England. Potentially another student could have a prolonged seizure at the same time as my son. What is the nurse to do in that situation? Both students need her help fast, but because the law does not allow anyone else to help administer seizure medication, she has to choose which child to care for. What if the nurse helped the other student but not my son, and he stopped breathing, and then his heart stopped? Surely, the teacher would call the paramedics, but that's more time wasted on waiting for help. Even when EMTs arrive, Hasbro is a 40 minute drive away. Imagine what kind of havoc is wrecked on a small child's body from seizing for so long. Imagine the worst case scenario as a very real possibility. Do you understand how scared that makes me feel as a parent? House Bill H5491 would eliminate that fear, because my sons' teachers could intervene.

I understand the apprehension that some school staff may have when it comes to giving medication. I'm not a nurse, and yet I have been easily trained by my son's healthcare team on how to give his emergency medications. The task is not hard. The medication my son needs (Diastat) is in a syringe that the pharmacist prepared in advance. This means there is no need to worry about measuring or overmedicating him. Anyone who is willing can learn how to administer it, and actually save his life. Because when you have a seizure, I promise you, every second counts. The good samaritan clause would protect anyone who decided to step in and save his life, should there be any adverse side effects. All we can do as human beings is try our best. Without this law, no one except the nurse is even allowed to try.

Please help me help my son. The Seizure Safe Schools Act could save his life.

Most Sincerely,
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Sent from my iPhone