

March 11, 2025

Dear House Committee on Education,

I am writing in support of Rhode Island House Bill 5491 to help make Rhode Island schools seizure safe. My daughter Faith was diagnosed with epilepsy a year and a half ago after having a seizure at home. That day is forever etched in my mind as I witnessed my child slump over and become unresponsive. She has a rare genetic condition, PTEN Hamartoma Tumor Syndrome, which increases her risk of having learning disabilities, certain forms of cancers, and epilepsy. While she hasn't had a seizure since the first one over a year ago, her doctors have told me that she will likely start having more seizures as she ages, which is why she takes daily anti-seizure medication (Levetiracetam). Additionally, the ability to have emergency seizure medication available to her at school (Valtoco) is critical to her care.

Managing the care of a child living with multiple health conditions is challenging and having a seizure action plan is essential to her being able to have the medication she needs in case of a seizure that lasts longer than 5 minutes (a seizure longer than that increases the likelihood of brain damage). Her school, Myron J. Francis, has been supportive in addressing Faith's needs and the school nurse has access to provide Faith with emergency seizure medication while she is in school. However, gaps certainly remain as her emergency seizure medication is not available to Faith during her after school program at the YMCA (held at the school) as there is no licensed nurse available to administer the emergency medication then (Faith's current seizure action plan letter from her doctor stipulates a medical professional must administer it). My hope is that the passage of RI House Bill 5491 will make emergency seizure medication for children more widely available at schools while also helping to create policy that will further educate teachers and school administrators about how to support children with epilepsy. I also hope that this important legislation will also lead to further adoption of access to emergency seizure medications at other child care facilities (day cares, after school programs, and summer camps) because that is also another area where gaps in access exist.

I wish that I could have been able to be at the hearing in person, but could not attend due to my work schedule. As such, I am submitting this letter in support of this bill.

Sincerely,

Felicia Salinas-Moniz, Ph.D.
Rumford, RI