



**Testimony to the  
HOUSE COMMITTEE ON EDUCATION  
Tuesday, March 11, 2025**

**IN SUPPORT OF H5491  
AN ACT RELATING TO EDUCATION -- HEALTH AND SAFETY OF PUPILS  
SEIZURE SAFE SCHOOLS ACT**

**Offered by  
Bill Murphy  
Director, Advocacy & Public Policy  
Epilepsy Foundation New England**

TO:

**Representative Joseph McNamara – Chair  
Representative Thomas E. Noret – First Vice Chair  
Representative Rebecca M. Kislak, Second Vice Chair  
Representative Nathan W. Biah  
Representative Julie A. Casimiro  
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Representative Ramon A. Perez  
Representative Robert D. Phillips  
Representative Earl A. Read, III  
Representative Sherry Roberts  
Representative Mary Ann Shallcross Smith  
Representative Brandon T. Voas  
Lisa Cataldi**

Thank you, Chairman McNamara, Co-Chairs and Members of the Committee for the opportunity to submit testimony in support of H 5491.

First, I want to thank Representatives Fogarty and the bill's co-sponsors for continuing to champion our cause.

To date, twenty-six (26) states have passed their version of the Seizure Safe Schools Act. Last year Connecticut passed their bill, and we hope Rhode Island will join this roster.

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Our mission is to help people and families affected by epilepsy in New England.  
We are an independent 501 (c)(3) nonprofit organization with tax identification # 22-2505819

Indeed, this bill, has been before this Committee before. The key difference this year is that, over the past few months, the Foundation has had the opportunity to work collaboratively with the Rhode Island Certified School Nurse Association and leading pediatricians, such as Dr. Gregory Fox and Dr. John Gaitanis Pediatric Neurologist at Hasbro Children's Hospital to address and resolve any concerns past versions had. We were thrilled to see the testimony the Nurses' Association submitted in support of this current version.

Epilepsy is the most common neurological condition among children.

One in ten Americans will experience a seizure in their lifetime and,

1 in 26 Americans will be diagnosed with epilepsy.

1 in 26, in some cases that is like saying one in a classroom!

More than 11,100 individuals are living with epilepsy here in Rhode Island. Of this number, more than 1,300 of them are school aged children living with active epilepsy.<sup>1</sup>

These students and their families want to be assured that if and when they have a seizure it will be dealt with appropriately.

This bill provides for consistency. Many schools already deal with seizures appropriately. Yet, we also hear from many where the school setting is a challenging one for students with epilepsy.

At one point, it was questioned if this bill was even needed? Wouldn't a student's IEP or 504 plan address the concerns we have?

H 5491 is more about seizure awareness and appropriate first aid and not specifically the educational needs or accommodations needed addressed in an IEP/504 plan. An IEP is an in-depth document for all students who require special education services. Not all students with epilepsy require special ed. services.

A 504 plan can accommodate students with a limitation or handicap that significantly impacts one or more essential life activities. Epilepsy is an "episodic disorder: In between seizures, the essential life activities of many students are not "significantly impacted" or impacted at all. Thus, many have simply been told they do not qualify for a 504 plan. In addition, I am not sure the epilepsy awareness and seizure first aid called for in this bill are defined as "accommodations".

To qualify for services (and an IEP), a student must meet two criteria. First, they must be formally diagnosed as having a disability as defined under the [Individuals with Disabilities Education Act](#) (IDEA). This federal law covers 13 categories of disability, one of which is "specific learning disabilities." Second, the school must determine that a student needs special

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<sup>1</sup> Centers for Disease Control and Prevention. Epilepsy Data and Statistics. Last updated November 18, 2018

education services in order to make progress in school and learn the general education curriculum. Not all students with disabilities meet both criteria.

Epilepsy can develop in anyone at any time for a whole host of reasons. If a student experiences their first seizure in school a 504 plan would not even be in place. But if staff had the training called for in this bill, they could, indeed, respond appropriately. And with 1 in 26 Americans having epilepsy, chances are a teacher or other staff member may have a seizure disorder. Thus, the training provided benefits the entire school community and not just students.

Requiring every student with epilepsy to have a 504 plan to simply assure appropriate first aid, if even feasible, would most certainly put an undue and costly burden on 504 Coordinators across the state.

Epilepsy is indeed a public health crisis. As mentioned, 1 in 26 Americans will be diagnosed with epilepsy. Many people do not realize that people can and do indeed die from seizure. Thus, H75491 helps to assure that the school community can indeed recognize a seizure and respond accordingly. And for those diagnosed with epilepsy a seizure action plan details how to respond to an individual's seizure from a medical/safety/and over all well-being for that individual.

As noted, this bill addresses these challenges in four main ways:

- It provides an easy to access seizure recognition and first aid training module for school personnel.
  - The training and all related materials are provided free of charge to schools and school personnel.
  - There are different training modules for available for different staff and are available as an in-person staff training or as an on-line training one can take at home at any time, at their convenience...on a Saturday morning enjoying their coffee!
  - An extra bonus is that both the on-line and in person training provide Continuing Education Credit or Contact hours approved by the national Centers for Disease Control.
- Second, it requires that a Seizure Action Plan is made part of the student's file and made available to school personnel and volunteers responsible for the student; This is a simple, but detailed, form with information and instructions specific to an individual student.
  - Many schools are already using this form, it is not new.
- H 5491 ensures that any FDA-approved medication prescribed by the treating physician is administered.

- This bill allows for age-appropriate epilepsy awareness programs for all students to dispel many of the myths and stigma that have surrounded epilepsy.

Again, these trainings and materials are free!

I appreciate your support of H 5491.

If you have any questions, please feel free to contact me at [wmurphy@epilepsynewengland.org](mailto:wmurphy@epilepsynewengland.org)