

## **AN ACT RELATING TO SEIZURE DISORDERS IN SCHOOLS, H 635 & S 422**

I am a student, daughter, sister, friend, peer, and—most importantly—an advocate for individuals living with epilepsy. My name is Cailin Lawlor, and I know firsthand the fear, uncertainty, and misunderstanding that come with this condition. As a 21-year-old pursuing a career in nursing, my mission is to ensure that individuals with epilepsy are recognized for their abilities and not defined by their diagnosis.

Living with epilepsy has shaped who I am and taught me resilience, perseverance, and the power of self-advocacy. Nearly 11 years ago, when I was diagnosed, I could never have imagined how much this condition would strengthen my commitment to advocacy and education or how it would open my eyes to the everyday challenges faced by those living with epilepsy. I am writing in the hope that my voice—and the millions of voices of those living with epilepsy—will be heard and acted upon to create meaningful change.

The Seizure Safe Schools legislation resonates deeply with me because it represents a future where students with epilepsy are protected, understood, and empowered. Students deserve teachers and staff who are trained to recognize triggers, identify warning signs, and respond safely. Education can reduce fear, break down stigma, and—most importantly—save lives.

Over a decade ago, during fifth-grade parent conferences, my parents were told, “She stares out the window.” Even though I loved laughing with friends at recess and participating in school activities, those “staring out the window” moments weren’t daydreams. They weren’t signs of disengagement. They were seizures—specifically, absence seizures, a type not widely understood. Today, stigma around epilepsy remains, and it can be just as dangerous. Not all seizures are visible, and not all fit the familiar stereotype of dramatic movements.

As my epilepsy progressed, I faced new challenges that affected my daily life, independence, and opportunities. During my senior year, my school told me that sitting on the floor was my only option. I am a student with a deep passion for learning, and I never wanted to be singled out because of my condition. Epilepsy is only a part of who I am and will never define or hinder my capabilities. Singling someone out, even for safety, can isolate them and affect their confidence and learning.

The night before prom, I was told I couldn't attend due to the risk that having a seizure would be too dangerous and disruptive. Instead, two family friends who were nurses went on my behalf and acted as chaperones. Despite their support, it was a stark reminder of how epilepsy can limit experiences and highlight the importance of awareness, understanding, and proper accommodations.

After years of living with intractable epilepsy and enduring gut-wrenching side effects, along with trying holistic approaches, I underwent a craniotomy in my senior year of high school. This experience was life-changing and reinforced the critical need for understanding, support, and advocacy for students living with epilepsy.

This is just a piece of the puzzle, a slice of the issue. By implementing education for school staff, awareness can increase, lives can be saved, and students can finally feel safe, understood, and supported. Through this legislation, we can reduce stigma, challenge stereotypes, and create learning environments where students feel valued. Teachers and staff must be empowered with the tools to support every student, ensuring that learning happens without fear.

As a college senior working at Boston Children's Hospital, I have seen firsthand the impact of patient education, advocacy, and compassionate care. Knowledge and preparation improve outcomes—not just in hospitals, but in schools. I share my story so that every student with epilepsy is seen, supported, and empowered—able to live fully and thrive beyond their diagnosis. With this legislation at the forefront, we have two options: ignore the need for change and risk preventable harm, or act to change the future, protect students, and honor the lives and potential of every child with epilepsy.