

SB299-Support

Education - Public and Nonpublic Schools - Seizure Action Plans (Brynleigh's Act)

February 3, 2022

Education, Health & Environmental Affairs Committee

11 Bladen Street

Annapolis, MD 21401

Dear Honorable Committee Members:

I write to you with appreciation for your consideration of this proposed legislation. My son Gavin was diagnosed with epilepsy at age 5 after experiencing two unprovoked seizures. Over the past 5 years, his epilepsy has thrown us many twists and turns including becoming refractory.

Gavin was in first grade. He was a great student, aimed to please and enjoyed school. I remember receiving a note about an incident in class just a few weeks prior to that new drug resistant label. The teacher wrote that Gavin abruptly got out of his seat and exited the classroom. She asked that I speak to him in regard to this being unacceptable. When I talked to Gavin about it, he was upset. He didn't remember it happening, but assured me he knew it was not ok to just get up and leave the classroom. He felt embarrassed for getting into trouble in front of his peers. In the weeks that followed, as his seizure activity ramped up, we ended up seeing these wandering episodes at home. We consulted with our neurologist and verified on EEG that they were in fact seizures. Because his teacher did not have seizure recognition training and Gavin presented with a new seizure type while in her care, he was unfortunately put into a situation where he was reprimanded rather than receiving appropriate seizure first aid.

Here is a fun fact- my other son, Gavin's older brother James, is **6'7" tall** at 13 years old. Yes, you read that right! Picture if you will a 6'7" Gavin sitting in class at Central Middle School. He gets up and walks out of the classroom. He is unsteady on his feet and seems to be saying something, but is not quite making sense. He is not following the orders of the classroom teacher or hall monitor.

In a situation like this, Brynleigh's Act would ensure the following-

1. Gavin's teacher would have received and reviewed a copy of his Seizure Action Plan. The SAP details the type of seizure's Gavin has.
2. School staff would have had training to recognize that what they see Gavin experiencing could in fact be a seizure even if they were not privy to his SAP.
3. School staff would have also been trained to respond by providing Seizure First Aid, which would include timing the seizure, clearing the area and keeping him out of harm's way.

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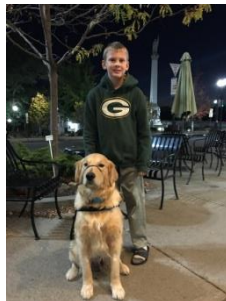
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4. If the seizure lasted greater than 5 minutes, there would be at least 2 individuals on site that have additional training to administer a rescue medication. So, if for example, the school nurse is at another assigned school that day, there is at least 1 other individual in the building qualified to give this extremely important time sensitive medication.

Without this type of legislation in place, we could be looking at a very different response.

Seizures have put Gavin in the fight for his life. He has had 3 brain surgeries. The most recent of which occurred in October. We spent 7 weeks away from home; 4 at Boston Children's and 3 at Kennedy Krieger. The repeated seizure activity and surgery resulted in deficits to the entire left side of his body. He has worked very hard retraining his brain and body how to walk and use his hand and arm. He is currently taking 5 antiepileptic drugs, and still, seizures persist. He is the epitome of bravery and resilience. He and I both are doing everything in our power to keep him safe and to give him the best quality of life possible. We need legislators like you to see the value in his life and day to day experiences. We need legislators like you to put these simple, but critical measures into place...our kids deserve to be in Seizure Safe Schools.

Respectfully,
Gavin's mom, Lauren DiBitetto



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