

HB0136-Support
Education - Public and Nonpublic Schools - Seizure Action Plans (Brynleigh's Act)
January 20, 2022

Ways & Means Committee
6 Bladen Street
Annapolis, MD 21401



Dear Honorable Committee Members:

I write to you with appreciation for your consideration of this proposed legislation. The preschool class photo to the right was taken in the spring of 2016. My sweet Gavin was 4 years old at the time. He was learning, growing, playing; a typical healthy little boy. A year later Gavin was diagnosed with epilepsy after experiencing two unprovoked seizures. Two years after his diagnosis his epilepsy became drug resistant. Since becoming refractory, Gavin 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.

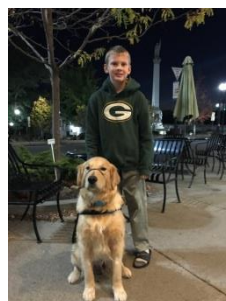
Another child in this class, Katie, would go on to have a single seizure in the summer of 2019. Coincidentally, Katie's mom brought our family a meal in the days following Gavin's first brain surgery. As a friend who lent support and a sympathetic ear, she had seizure awareness that allowed her to act with knowledge during her own daughter's experience.

Unfortunately, epilepsy can be very isolating and seizures can carry a stigma, but the reality is that seizures and seizure disorders are quite common. With statistics like 1 in 26 people being diagnosed with epilepsy and 1 in 10 people experiencing a seizure during their lifetime, chances are you know a Gavin or a Katie too. Seizures have been identified as one of the top 3 emergencies in schools. In addition to the 7,900 students who have diagnosed seizure disorders in the state of Maryland, it would not be unheard of for school personnel to find themselves responding to a student that has had a seizure as a result of becoming overheated during PE, for example. You do not have to have a seizure disorder to experience a seizure. The day that preschool class picture was taken no one would have thought that seizures would become a part of Gavin and Katie's story. Our school communities deserve the tools to act from a place of awareness, knowledge and preparedness when handling seizures. By passing Brynleigh's Act, we can ensure that will happen.

Respectfully,

Gavin's mom, Lauren DiBietto

Lauren DiBietto
3614 Conch Drive
Edgewater, MD 21037



rappla@hotmail.com
908-619-2860