

March 3, 2020

SUPPORT – BRYNLEIGH'S AC – SB0549

To the Members of the Education, Health and Environmental Affairs Committee,

My name is Heidi Denlinger, and I am writing to you as a parent of a child with epilepsy in support of SB 549. This bill would require the training of school nurses and personnel in seizure recognition and first-aid response as well as educate students about epilepsy, making the schools a safer environment for students with epilepsy and seizures. This bill would require that schools have a Seizure Action Plan for each student on file and available to all personnel responsible for the student, ensure the administration of FDA-approved medications, and includes a Good Samaritan Clause for those acting in good faith in accordance with the bill's provisions.

My daughter, Emma, was one of the 0.6 percent of children affected by epilepsy. Emma began experiencing absence seizures at the age of 10 years. These are brief (up to 10 second) staring spells that are often difficult to detect and often mistaken for daydreaming and can occur up to hundreds of times per day, wreaking havoc with attention and learning. Emma was completely unaware that she was experiencing them.

When she was diagnosed in the summer following the 5th grade, her father and I wondered how long she had been having them without us knowing it. During the previous school year, Emma's teachers had contacted us to tell us about a change they had noticed in her academic behavior and that she was forgetting assignments. They did not know what it was.

After her diagnosis, when my husband and I researched out these seizures, we read that many times they are discovered by teachers because they tend to face the students throughout the day and notice when the student suddenly stops talking midsentence or stops moving for several seconds.

I now feel that if Emma's teachers had been better educated on the different types of seizures, Emma's seizures may have been detected months earlier, getting her treatment sooner and lessening the impact on her education and self-esteem. Later, following her diagnosis, Emma struggled through a couple of medications, trying to get her seizures controlled. When she started 6th grade, the burden was on us to yearly educate the teachers and school healthcare personnel as to what her seizures looked like and how to react to them.

Because Emma was older when she was diagnosed with absence seizures, neurologists told us that she had a 50 percent chance of them developing into convulsive seizures. This fact was also relayed to her teachers, which always seemed to create fear amongst many of them. There were some who seemed to understand epilepsy to some extent due to having had a student before or a family member with it, but for many of them, this was a new experience, and they seemed to fear the possibility of a convulsive seizure occurring in their class, and not really knowing how to react to such an event. Also, every year, there were always a couple of teachers that could not make it to Emma's pre-school epilepsy education meeting and would later discriminate against her because they did not understand the diagnosis.

As she grew older, Emma was forced to become her own advocate and had to educate her teachers of her epilepsy and how it might affect her (and them). Although, I was proud of how my daughter went from a child who did not want anyone to know of her epilepsy due to fears of bullying from peers

because of the stigma of epilepsy and the lack of education on it in the community, to a strong and courageous voice advocating and educating about epilepsy for not only herself, but for others with epilepsy without so loud a voice, I wish that the school system had done more. I wish that school systems would do more to educate their staff and students about epilepsy and seizures, so that kids with epilepsy can do less educating and advocating for themselves about their epilepsy and focus on their educations and enjoying their school experience.

When parents send their child to school, they are entrusting the safety and wellness of that child to the school personnel for that day. For parents with a child with epilepsy, it is much harder to have that trust due to the ignorance that exists in the school system and community at large about epilepsy and seizures. For those parents, they will have to carry the fear that their child may be discriminated against by well intentioned, but unknowledgeable teachers and coaches because of their fears of seizures; that their child may not receive rescue medication in a timely fashion to prevent unnecessary seizing, possibly harming their child; that their child may be laughed at or bullied or feel lesser than because their fellow students are uneducated about epilepsy. SB 549 will not completely erase all their fears, but it will go a long way to making them and their student with epilepsy feel safer and more secure. I believe that is something very valuable and worth fighting for.

I believe that education is empowering. SB 549 would empower school staff and students through epilepsy and seizure education and training. Please support SB 549 and make our schools a safer place for students with epilepsy!

Sincerely,

Heidi Denlinger
6900 South Carlinda Ave.
Columbia, MD 21046
heididenlinger@verizon.net