

March 3, 2020

To the members of the Education, Health, and Environmental Affairs Committee:

My name is Keri Hyde, and I am the parent of a young adult with Epilepsy.

I am in full support of SB 0549 "Seizure Action Plans"/Brynleigh's Act.

Our journey with seizures began when my daughter was in middle school. As if middle school isn't difficult enough to navigate, she now had to deal with teachers, administrators and peers that made her path even more difficult. Had this legislation been in place when she was younger, school personnel would have been much better prepared when she had a seizure at school. She would have felt infinitely safer knowing that staff had been trained to the standards of the Epilepsy Foundation of America. Initially, she had absence seizures, so it could appear that she was just staring off into space. With the proper training, teachers and staff would have recognized more quickly what was happening and would have been able to time the seizure per her doctor's orders. Her seizure action plan would have included that, and we would have had that valuable information to share with her neurologist. Unfortunately for her that wasn't the case. Some teachers completely ignored the symptoms of the seizure, and one even had another student "act out" having a seizure during a literature class to the laughter of the other students. Think about that for a minute.

Equally important is the education of the students, the peers of the child that has Epilepsy. I completely understand how difficult it is to add to an already full curriculum, I taught elementary school. I know that "one more" thing added to what is already required is a challenge. But living with Epilepsy is more of a challenge. Imagine not knowing if you are going to have a seizure and knowing that if you do the students in your class will not understand and may be frightened. And after having a seizure, being treated differently, not invited to events and teased. Being terrified that when you are having a seizure that someone will take a video of it and post it. Education about seizure disorders can change that. Of course, there are still going to be insensitive people, but understanding something makes it less frightening. The facts are there: Epilepsy is the 4th most common neurological problem. 1 in 26 people will develop Epilepsy at some point in their lives. Not addressing the needs of the children that have been diagnosed is not acceptable.

Children that have a diagnosed seizure disorder deserve nothing less than a safe school environment that has a specific plan to meet their needs. All schools should be educating teachers, students and other school personnel consistent with the guidelines of the Epilepsy Foundation of America. During this journey with my daughter, I have met so many people that have been impacted by seizures and not one had the same story to tell. Each case is different and should be treated as such through the development of a seizure action plan that addresses the unique nature of each child that has been diagnosed.

I urge you to support this important legislation.

Thank you,

Keri Hyde