

Written Testimony of Lauren Shillinger
Ways and Means Committee
January 20, 2022
HB0136 - Seizure Action Plans - Brynleigh's Act
Position: Support

Hello, my name is Lauren Shillinger and this act is named after my daughter, Brynleigh. I would like to begin by thanking the Ways and Means Committee for hearing my testimony today.

In 2014, at 9 ½ months, Brynleigh began having seizures and spent a week at Children's National Medical Center. After an EEG and full body scans she was diagnosed with Epilepsy and a rare genetic disorder called "Tuberous Sclerosis Complex." This genetic disorder causes tumors to grow in all major organs and is the leading genetic cause of both autism and epilepsy. Our doctors prescribed Brynleigh numerous anti-seizure medications, but they failed to work for her, meaning she was having more than 25 seizures a day. In October 2016 she had two brain surgeries to remove the majority of her left temporal lobe and reduce her number of seizures. Thankfully the surgery did reduce her seizures, but she still has tumors in her brain and can have seizures at any time. She recently had a third brain surgery in October 2021.

As Brynleigh grew she continued to take anti-seizure medications daily and we had to carry a seizure rescue medication at all times, to interrupt the two most dangerous conditions if they occurred: a cluster of seizures, or a seizure that won't stop, potentially leading to brain damage. As we approached the time for her to begin preschool, I started to worry about how this would impact her future. Not to mention, how would it change her daily life? How would she be able to attend school safely?

As that time approached, we met with her team to prepare for her to begin preschool. We shared our concerns that we were scared for her to attend school. As a mother I was as anxious as when we had handed our daughter over for brain surgery.

Her teachers and team shared the same concerns that they were scared too. They had never been trained on dealing with students with seizures or seizure rescue medications. For most parents the start of school is filled with the excitement of getting a new backpack and school supplies, while our time was filled with anxiety and determining how best we could prepare her team. How would they know what to look for to recognize a seizure? How would they help her? Who would administer her rescue medication?

Now that Brynleigh is in first grade we still continue to have these same fears and concerns daily. We knew we had to make a change so that we will not be faced with this fear every year until she graduates from high school.

In December 2019, we contacted the honorable Delegate Kenneth Kerr in the hope that he would help us create seizure safe school legislation, as we were concerned not only about our daughter Brynleigh, but also the almost 8,000 students and the approximately 59,900 adults in Maryland living with seizures and epilepsy.

Currently, there are twelve states in the country that have laws to protect children who have seizures during the school day. Fifteen more are looking at similar legislation right now, so this is important and timely. It is our hope that Maryland will be the next state to train teachers and school staff in seizure recognition and first aid. This critical online training is free and already

created by the National Epilepsy Foundation and only takes approximately 45 minutes to complete, which we have taken with our daughter's team. We believe 45 minutes annually to potentially save lives is a small request. Tragically, children do die from seizures as they can be life threatening and can also lead to permanent brain damage if not responded to timely and properly.

By enacting this life saving legislation, Maryland would be protecting almost 8,000 children (age 0 to 17) with epilepsy and seizures, not to mention those who have a single seizure while in school. If House Bill 136 becomes Brynleigh's Act, 16,000 Maryland parents, including myself and my husband, would sleep better every night knowing that our children are as safe as possible in school.

In addition to being Brynleigh's mom, I am a volunteer, fundraiser and advocate for both TSC and Epilepsy research and education. We want to be her voice since she is unable to be her own advocate. Passing this bill would ensure adequate training is provided and will make our schools seizure safe. I urge you to please support and vote yes to Brynleigh's Act which will make a world of difference for our children. Thank you for your time.



Sincerely,

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