

*Written Testimony of Lauren Shillinger
January 20, 2021
Support
SB225
Brynleigh's Act*

Good afternoon my name is Lauren Shillinger and I am Brynleigh's mother for whom this bill is named after. I'd like to thank the Education, Health and Environmental Affairs Committee for hearing my testimony today.

In August 2014, at 9 ½ months, Brynleigh began having complex partial seizures. We were referred to 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. Thankfully the surgery did reduce her seizures, but she still has tumors in her brain and can have seizures at any time.

She continued to take anti-seizure medications daily and we had to carry a seizure rescue medication at all times, to interrupt a dangerous cluster of seizures or a seizure that won't stop, potentially leading to brain damage. I started to worry about how this would impact her future. How it would change her daily life? Would she be able to attend school?

We met with her team to prepare for her to begin preschool. We shared our concerns and I was as anxious as when we had handed our daughter over for brain surgery.

Her teachers and team 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 recognize a seizure? How would they help her? Who would administer her rescue medication?

Now that Brynleigh is in Kindergarten we still continue to have these same fears and concerns daily. We don't want to be faced with this fear every year from Kindergarten until she graduates from high school.

By enacting this 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 Senate Bill 225 becomes Brynleigh's Act, 16,000 Maryland parents, like myself and my husband, would sleep better every night knowing that our children are as safe as possible in school.

This critical 45 minute training is free and already created by the National Epilepsy Foundation and only takes approximately 45 minutes to complete. We believe this life saving training 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. Passing this bill would ensure adequate training is provided to 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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