



March 3, 2020

SB 0549 – BRYNLEIGH'S ACT-- SUPPORT

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

My name is Sarah Pinsker, and I'm writing to you as the Program Coordinator of the Epilepsy Foundation Maryland, a chapter of the national Epilepsy Foundation. Our mission is to lead the fight to overcome the challenges of living with epilepsy or seizures and to accelerate therapies to stop seizures, find cures, and save lives.

Prior to joining the new EF Maryland chapter, I worked at Abilities Network and the Epilepsy Foundation of the Chesapeake Region for twelve years. I've personally trained everyone from school staff to senior centers to teenagers to the staffs of federal agencies.

Approximately 59,900 people in Maryland live with epilepsy, including 7900 children. That's roughly 1 in 26. An even bigger number, 1 in 10 people, will have a single seizure in their lifetime. That can include students or staff: the teacher who slips on the cafeteria floor and hits her head; the athlete who overheats in gym. Some of those people will arrive at school with diagnoses known, but many more will have their first seizure in school. If nobody recognizes them for what they are, they can progress to other, worse types of seizure.

Currently, anyone who wants can request that we provide seizure training for their staff. What usually happens is a child is diagnosed, and the parents request that their school personnel be trained to make their child's experience safer. Some schools respond positively and let us train their entire staff. Others limit the attendees to the immediate classroom teachers for that student, which doesn't keep them safe in the hallway, in gym class, in the lunch room, etc. Still others don't respond, or can't find the time, or say the nurse will handle it, leaving parents concerned for their children's safety. A seizure can be every bit as deadly as an anaphylactic allergic reaction or a bad asthma attack, and often requires the same rapid response.

School nurses are wonderful, but they are not enough. According to the National Education Association, there are 913 students per school nurse in Maryland. Some districts share nurses between multiple schools. A student in need of emergency intervention—a seizure going longer than five minutes, or a cluster of seizures, for example—can't wait for emergency services to arrive.

I've heard the argument that a student's IEP or 504 plan should cover this, but that is not the case. Not all students with seizures have IEPs or 504s. Many don't need any accommodations under those laws, and many will have their first seizure while in school, with no plan or expectation that it will happen. They would still be safer in a school where personnel are trained to recognize and respond to seizures.

The Epilepsy Foundation's training for school personnel was developed in conjunction with the CDC. It's available for free online, and already up and working for anyone who wants to take it. Five other states are already using it, and ten more have introduced similar legislation. It provides a solid overview of seizure recognition and response.

Maryland students deserve to be able to learn in a safe environment, and all parents deserve to know that school personnel are properly equipped to care for their children's health needs. The simple steps in this bill can save lives. Thank you for your support of Brynleigh's Act, HB 0675.

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