

December 22, 2020

To Whom It May Concern,

On behalf of the Tuberous Sclerosis Alliance (TS Alliance), I am writing in support of the Maryland Seizure Safe School Act, or Brynleigh Act, which calls for state legislation to ensure all school personnel, including nurses, teachers, and volunteers, are not only prepared but can recognize and respond appropriately and efficiently to students experiencing seizures. Approximately 1 in 26 people will develop epilepsy in their lifetime; 1 in 10 people will have a single seizure in their lifetime; approximately 7,900 Maryland children currently have an active epilepsy diagnosis, but there is only one nurse per 913 students.

Tuberous sclerosis complex (TSC) is a genetic disorder that causes tumors to form in many different organs, primarily in the brain, eyes, heart, kidney, skin and lungs. The aspects of TSC that most strongly impact quality of life are generally associated with the brain: seizures, developmental delay, intellectual disability and autism. We estimate over 1,008 individuals in Maryland are affected by TSC. Seizures remain one of the most common neurological features of TSC, occurring in 85% of individuals with TSC. Additionally, more than 50% of individuals with TSC who have epilepsy will not respond to standard antiepileptic medications and have intractable epilepsy. TSC is a lifelong disorder.

It is critical to the TSC and epilepsy communities that school staff know how to recognize and respond to a seizure should one occur in their classroom, school bus, or specialized area. Quick response is vital and cannot wait for a school nurse to arrive, making it essential that all school personnel have training and familiarity with seizure recognition. Many students will have their first seizure while in school, so this is not just a matter of following a plan that is already in place.

The Brynleigh Act will ensure that all school personnel have some familiarity with seizure recognition, and in doing so, will make all our children safer in their school environment. Five other states have passed similar bills, and many other states will follow. We hope that Maryland will, as always, lead by example. We stand with the Epilepsy Foundation in supporting this legislation.

Based in Silver Spring, Maryland, the TS Alliance is the only national organization dedicated to finding a cure for TSC while improving the lives of those affected.

Sincerely,



Kari Luther Rosbeck
President and CEO