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

Dear Delegate Vanessa E. Atterbeary,

On behalf of the TSC Alliance, I am writing in support of the Maryland's Seizure Safe School Act, "Brynleigh's Act," or HB.136, which calls for state legislation to ensure that all school personnel, including nurses, teachers, and volunteers, are prepared to recognize seizures and are able to 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.

Based in Silver Spring, Maryland, the TSC Alliance is the only national organization dedicated to finding a cure for tuberous sclerosis complex (TSC) while improving the lives of those affected. TSC is a lifelong 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.

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. Students with TSC will likely experience multiple seizures while at school, some may require rescue medication.

HB.136 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. Twelve 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.

Sincerely,

A handwritten signature in black ink, appearing to read "Kari Luther Rosbeck".

Kari Luther Rosbeck  
President and CEO

**Hope no matter how complex**

A decorative graphic at the bottom of the page consisting of three thick, curved lines in blue, orange, and purple, sweeping from the left towards the right.

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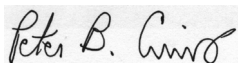
Dear Delegate Atterbeary,

We are writing in support of the Maryland Seizure Safe School Act, or Brynleigh's Act or HB0136, 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, and approximately 7900 Maryland children currently have an active epilepsy diagnosis, but there is only one nurse per 913 students. It is of vital importance 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 to a seizure is vital and cannot wait for a nurse to arrive. It is not enough for school nurses to be the only ones with that training. 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.

As Director of the Clinical Center for Adults with Neuro-Developmental Disabilities and the TSC Center of Maryland, many of our patients are adolescents and teenagers currently attending Maryland public and private schools. The need for a school safety plan for seizures is an imperative.

Brynleigh's 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. Twelve 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.



Peter B. Crino, MD, PhD  
Professor and Chairman  
Department of Neurology  
Director, Clinical Center for Adults with Neuro-Developmental Disabilities  
Director, TSC Center of Maryland  
University of Maryland School of Medicine  
University of Maryland Medical Center  
215-908-928





*Seizure Action Plans save lives  
Do you have one?*

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Position: Support

Dear Delegate Vanessa E. Atterbeary,

We are writing in support of the Maryland's Seizure Safe School Act "Brynleigh's Act" or HB.136, which calls for state legislation to ensure school personnel, including nurses and teachers, are not only prepared but can also recognize and respond appropriately and efficiently to students experiencing seizures. Although approximately 1 in 26 people will develop epilepsy in their lifetime, 1 in 10 people will have a single seizure in their lifetime, and approximately 7,900 children in Maryland currently have an active epilepsy diagnosis, there is only one nurse per 913 students. It is vitally important for school staff to know how to recognize and respond to a seizure should one occur in the classroom, school bus or specialized area. Quick response to a seizure is crucial and cannot wait for a nurse to arrive. It is not enough for school nurses to be the only ones with this training.

The Seizure Action Plan (SAP) Coalition was formed to educate people with epilepsy, their caregivers and healthcare professionals about seizure emergency rescue protocols and the importance of personalized seizure action plans. The partnering organizations include the Dravet Syndrome Foundation (DSF), Lennox-Gastaut Syndrome (LGS) Foundation and TSC Alliance<sup>®</sup>. The mission of DSF is to aggressively raise funds for Dravet syndrome and related epilepsies; support and fund research; increase awareness; and provide support to affected individuals and families. The LGS Foundation is a nonprofit organization dedicated to improving the lives of those impacted by LGS through research, education and family support programs. The TSC Alliance is an internationally recognized nonprofit dedicated to finding a cure for tuberous sclerosis complex, while improving the lives of those affected.

HB.136 will ensure all school personnel have some familiarity with seizure recognition and in doing so will make all our children safer in their school environments. Twelve other states have passed similar bills, and many other states will follow. We appreciate the state of Maryland leads by example. We stand with the Epilepsy Foundation in supporting this legislation.

Sincerely,  
Dravet Syndrome Foundation  
Lennox-Gastaut Syndrome Foundation  
TSC Alliance





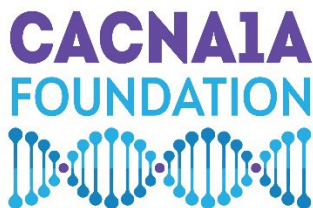
*Seizure Action Plans save lives  
Do you have one?*

**Additional Organizations Signing on to this Letter:**

Alliance for Genetic Etiology in  
Neurodevelopmental Disorders and Autism  
Autism Science Foundation  
Batten Disease Support and Research  
Foundation  
BPAN Warriors  
CACNA1A  
CFC International  
Child Neurology Foundation  
Coalition to Cure CHD2  
COMBINEDBrain  
CureGRIN  
CureSHANK3  
DEE-P Connections  
Dose Syndrome Epilepsy Alliance  
Dup15Q Alliance  
Families SCN2A  
Glut1 Deficiency Foundation  
Hope for HIE  
Hope for Hypothalamic Hamartomas  
International Foundation for CDKL5 Research  
International SCN8A Alliance

KCNQ2 Cure  
KIF1A.org  
Koolen-de Vries Syndrome Foundation  
Lightning and Love Foundation  
Malan Syndrome Foundation  
Mickie's Miracles  
NORE Institute  
PACS1 Syndrome Research Foundation  
PCDH19 Alliance  
Phelan-McDermid Syndrome Foundation  
Ring 14 USA  
SLC6A1 Connect  
SNAP25 Foundation  
STXBP1 Foundation  
SynGAP Research Fund  
SynGAP1 Foundation  
Tbc1d24 Foundation  
TESS Research Foundation  
The Brain Recovery Project: Childhood Epilepsy  
Surgery Foundation  
The Cute Syndrome Foundation  
The Epilepsy Foundation Maryland







# AGENDA

Alliance for Genetic Etiologies  
in Neurodevelopmental  
Disorders and Autism



**AUTISM SCIENCE FOUNDATION**

SEARCHING  
SOLVING  
SHARING



**IFCR**

**International Foundation  
for CDKL5 Research**



**MALAN SYNDROME  
FOUNDATION**



**KDVS**

Koolen-de Vries Syndrome Foundation



**thebrainrecoveryproject**

CHILDHOOD EPILEPSY SURGERY FOUNDATION



**KCNQ2  
Cure**.ORG

unity. hope. strength. love.





[www.G1DFoundation.org](http://www.G1DFoundation.org)