Kennedy Krieger Institute
Research. Treatment. Education.

Ryan E. Gill, MD, FAAP
Assistant Professor
Neurology & Developmental Medicine
801 N Broadway
Baltimore, MD 21205
Office: 443-923-2746
gillr@kennedykrieger.org

Education, Health, and Environmental Affairs Committee
January 20, 2022
SB299 - Seizure Action Plans – Brynleigh's Act
Position: Support

Dear Chairman Pinsky,

I am writing in support of the Maryland Seizure Safe School Act, or be Brynleigh's Act or SB299, which cause for state legislation to ensure all school personnel, including nurses, teachers, and volunteers, are not only prepared the can recognize and respond appropriately in officially to students experiencing seizures. Approximately 1 in 10 people will have a seizure in their lifetime, and 1 in 26 people will go on to develop epilepsy in their lifetime. There are nearly 60,000 people living with epilepsy in the state of Maryland, of which 7900 are children.

Despite the prevalence of epilepsy, seizures and seizure first-aid are still highly misunderstood by the public. Seizures in children can be particularly difficult to recognize. It is critically important that teachers and other school staff know how to recognize and appropriately respond to a seizure should one occur in the classroom, on the school bus, or other specialized school area. Timely response to a seizure is vital- delayed responses can have detrimental outcomes. Waiting for a nurse to arrive at the scene of a child having a seizure is not appropriate or safe. It is not acceptable for the school's nurse to be the only one who has been to respond to a seizure. There is only one nurse per 913 students in the state of Maryland.

As a neurodevelopmental pediatrician and Director of the Tuberous Sclerosis Clinic at Kennedy Krieger Institute, many of my patients are children and adolescents currently attending Maryland public and private schools. Far too often I have heard families share stories of their child experiencing a seizure in school and the less than ideal responses that took place.

Brynleigh's Act will ensure that all school personnel have familiarity with seizure recognition, and in doing so, we will make our children safer. Twelve other states have passed similar bills, and many other states will follow. We hope that Maryland will, as always, lead by example.

I stand with the Epilepsy Foundation in supporting this legislation.

Thank you for your time and support,

Ryan E

Ryan E. Gill, MD
Assistant Professor
Neurology & Developmental Medicine
Director, Tuberous Sclerosis Clinic
Kennedy Krieger Institute
Johns Hopkins University School of Medicine

UNIVERSITY of MARYLAND
SCHOOL OF MEDICINE

Peter B. Crino, MD, PhD
Professor and Chairman

Department of Neurology
110 S. Paca Street, 3S124
Baltimore, MD 21201
Office: (410) 328-2172
Fax: (410) 328-3449
pcrino@som.umaryland.edu

Education, Health and Environmental Affairs Committee
February 3, 2022
SB.299 - Seizure Action Plans - Brynleigh's Act
Position: Support

Dear Chairman Pinsky,

We are writing in support of the Maryland Seizure Safe School Act, or Brynleigh's Act or SB.299, 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

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

TSC Alliance®

8737 Colesville Road, Suite 400 | Silver Spring, MD 20910
800-225-6872 | info@tscalliance.org | tscalliance.org

Education, Health and Environmental Affairs Committee
February 3, 2022
SB.299 - Seizure Action Plans - Brynleigh's Act
Position: Support

Dear Chairman Pinsky,

On behalf of the TSC Alliance, I am writing in support of the Maryland's Seizure Safe School Act, "Brynleigh's Act," or SB.299, 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.

SB.299 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,

Kari Luther Rosbeck

Kari Luther Rosbeck
President and CEO

Seizure Action Plans save lives
Do you have one?

Education, Health and Environmental Affairs Committee
February 3, 2022
SB.299 - Seizure Action Plans - Brynleigh's Act
Position: Support

Dear Chairman Pinsky,

We are writing in support of the Maryland's Seizure Safe School Act "Brynleigh's Act" or SB.299, 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®. 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.

SB.299 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

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
Doose Syndrome Epilepsy Alliance
Dup15Q Alliance
FamilieSCN2A
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
NORSE 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

BPANWARRIORS.ORG
you are not alone

CFC International
Cardio-Facio-Cutaneous Syndrome

CCC
COALITION
TO CURE CHD2

COMBINED

DEE-P
CONNECTIONS

NORSE
INSTITUTE

PACS1 FOUNDATION
to find a cure for pacs1

SLC6A1
Connect

SNAP25
Foundation

PHELAN-McDERMID SYNDROME
FOUNDATION
pmsf.org™

STXBP1 Disorders
Leading the Charge For a Cure

SYNGAP1
FOUNDATION
RESEARCH EDUCATION ADVOCACY©

TBC1D24
FOUNDATION

CACNA1A
FOUNDATION

Lightning and Love
FOUNDATION
WWW.LIGHTNINGANDLOVE.ORG @LIGHTNINGANDLOVE

TESS
RESEARCH
FOUNDATION
for SLC13A5 Epilepsy

AGENDA
Alliance for Genetic Etiologies
in Neurodevelopmental
Disorders and Autism

International
SCN8A
ALLIANCE
Collaborating for a cure

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.

SCN2A RELATED AUTISM & EPILEPSY
FAMILIESCN2A®
FOUNDATION
WWW.SCN2A.ORG

SRF

together we believe
Dup15q
Alliance
together we achieve

HOPE
for HIE

SCN8A
EPILEPSY
The Cute Syndrome
FOUNDATION
www.TheCuteSyndrome.com

IFCR
International Foundation
for CDKL5 Research

Glut1
Deficiency
Foundation
www.G1DFoundation.org

CSNK2A1
FOUNDATION