



**DATE:** January 20, 2022                      **COMMITTEE:** House Ways and Means  
**BILL NO:** House Bill 136  
**BILL TITLE:** Education - Public and Nonpublic Schools - Seizure Action Plans (Brynleigh's Act)  
**POSITION:** Support with amendment

**Kennedy Krieger Institute supports House Bill 136 - Education - Public and Nonpublic Schools - Seizure Action Plans (Brynleigh's Act)**

**Bill Summary:**

HB136 requires, beginning in the 2023-2024 school year, at least two school personnel in each school to be trained in certain seizure recognition and response methods. Each school will provide training every two years to school personnel designated.

**Background:**

Epilepsy is a neurological disorder characterized by a tendency to have recurrent, unprovoked seizures. Epilepsy affects up to 1 percent of children in the United States (1). Incidence is greater in economically disadvantaged populations (1, 2). Children with epilepsy are more likely to miss school as compared to students with other health concerns (3), and subsequently miss out on opportunities to enhance their neurodevelopmental growth, as well as cognitive and adaptive skills. Therefore, collaboration between school personnel, families of children with epilepsy, epilepsy specialists, and epilepsy organizations is critical to optimize the quality of life for children with epilepsy.

A seizure can have various manifestations including staring, pause in activity, facial twitching, eyelid fluttering, falls or even jerking of one or all extremities. Seizures are usually unpredictable. Data suggest that once a seizure lasts for more than 5-10 minutes, it is unlikely to stop spontaneously within the next few minutes (4). Death or permanent disability can occur, albeit rarely, as a result of status epilepticus. More often, serious consequences occur hours or days later as a result of prolonged muscle stress, cardiorespiratory compromise and other complications such as organ failure (5). Therefore, current medical guidelines recommend immediate treatment of children with seizures lasting more than 5 min to prevent progression to status epilepticus and neurological injury (6).

**Rationale:**

Schools may be ill-equipped to meet the complex healthcare needs of school children with epilepsy due to inadequate training of school personnel in managing seizures as well as barriers to administration of seizure medication. Failure to effectively treat and manage seizures can have serious consequences for the child including status epilepticus (i.e., a prolonged and potentially life threatening seizure), permanent neurological injury, and death. More broadly, such failure leads to elevated health care costs for society.

**Management of seizures in school:**

School nurses play a crucial role in supporting students with epilepsy at school and ensuring their safety (7). The school nurse should be informed by the child's guardians if there is a history of any type of seizure for any student in his/her care (5). A student-centered seizure action plan should be developed that lists seizure type and treatment, describes basic and emergency first aid procedures and outlines specific interventions (5). Developing this the plan requires collaboration amongst school personnel, student, guardians, and the student's epilepsy healthcare team.

Children with epilepsy may be prescribed an antiseizure “rescue” medication for use in emergency situations such as clusters of back-to-back seizures, or prolonged seizures (typically seizures not abating at 5 minutes). The Epilepsy Foundation specifically recommends that the school nurse engage proactively with the student’s parents and healthcare team to clarify indications and instructions for rescue medication’s use (5). The student’s seizure action plan should clearly outline instructions for administration of rescue medications including name of the antiepileptic medication, dosage, dosing regimen, parameters of administration, route of administration, potential side effects, and how to monitor for effectiveness or lack thereof. Rectal administration of diazepam gel is one of the most widely used rescue medications and is generally well tolerated (8). However, rectal administration may create hesitation for school staff as well as social stigma for the patient. Other rescue medications approved for children in specific age groups are intranasal midazolam and intranasal diazepam. Intranasal formulations circumvent the social stigma and discomfort associated with rectal diazepam. Common side effects of all these medications sedation and difficulty with coordination. Rarely, cardiorespiratory instability requiring emergency medical care may be seen. All of these medications are available in premeasured dosing amounts based on age and weight of the child, and may improve safety of administration in the school setting (8). On occasion, the child’s seizure may not abate after administration of rescue medications and emergency medical services may need to be called. On other occasions, side effects such as cardiorespiratory instability may necessitate emergency medical care. The student’s seizure action plan should provide guidance regarding criteria on when to seek emergency medical care. It is important to keep in mind that the school setting encompasses not only the classroom but also bus transportation and off-campus activities such as field trips. School nurses may not be available in all situations (8). Therefore, we recommend basic seizure management training for all school personnel, including athletic coaches and school bus drivers. Studies support that such education measures improve confidence of personnel in taking care of children with epilepsy (7).

**Amendment:**

While the Kennedy Krieger Institute supports House Bill 136, we are concerned with one potential unintended consequence of the bill in its current form related to Section 1.F.II. which states that a parent or guardian of a student provides the “prescribed medication in an unopened, sealed package with the label affixed by the dispensing pharmacy”. The most common medication used in a seizure emergency in children is rectally administered diazepam. The diazepam rectal gel is packaged and sold as a sealed twin pack, with each pack containing two prefilled syringes of diazepam gel. Caregivers are typically advised to keep one syringe at home and provide one syringe to the school. The bill as written would require caregivers to purchase two twin packs, resulting potentially in higher copays or other out of pocket expenses which could be a hardship for some families. We recommend amending the language of the bill so that this potential inequity can be avoided.

**Conclusion:**

School-going children and adolescents living with epilepsy may experience seizures, including seizure emergencies, in school and school-associated settings. Administering a seizure rescue medication can abort the seizure and may improve health outcomes for children with epilepsy, decrease emergency care visits and inpatient hospitalizations, and subsequently shorten time away from class. Therefore, we advocate for training of school nurses in administration of anti-seizure rescue medications, and training of all school personnel in management of seizure emergencies. We anticipate that this will enhance learning and academic success for all children. We are concerned about a potential unintended consequence of the bill’s language in Section 1.F.II and recommend modification as addressed above.

**References**

1. Russ SA, Larson K, Halfon N. A national profile of childhood epilepsy and seizure disorder. *Pediatrics*. 2012;129(2):256–264[PubMed]
2. Camfield P, Camfield C. Incidence, prevalence and aetiology of seizures and epilepsy in children. *Epileptic Disord*. 2015 Jun;17(2):117-23. doi: 10.1684/epd.2015.0736. PMID: 25895502.

3. Pastor PN, Reuben CA, Kobau R, Helmers SL, Lukacs S. Functional difficulties and school limitations of children with epilepsy: findings from the 2009–2010 National Survey of Children with Special Health Care Needs. *Disabil Health J*. 2015. DOI: 10.1016/j.dhjo.2014.09.002.
4. Shinnar S, Berg AT, Moshe SL, Shinnar R. How long do new-onset seizures in children last? *Ann Neurol*. 2001 May;49(5):659-64. PMID: 11357957.
5. *Managing Students with Seizures. A quick reference guide for school nurses. 2ND ed. 2009. Epilepsy Foundation. 17598\_text-R2:17598\_text-R2 (nwesd.org)*
6. Cross JH, Wait S, Arzimanoglou A, Beghi E, Bennett C, Lagae L, Mifsud J, Schmidt D, Harvey G. Are we failing to provide adequate rescue medication to children at risk of prolonged convulsive seizures in schools? *Arch Dis Child*. 2013 Oct;98(10):777-80. doi: 10.1136/archdischild-2013-304089. Epub 2013 Jul 30. PMID: 23899921; PMCID: PMC3786609.
7. Austin JK, Kakacek JRM, Carr D. Impact of Training Program on School Nurses' Confidence Levels in Managing and Supporting Students With Epilepsy and Seizures. *The Journal of School Nursing*. 2010;26(6):420-429. doi:10.1177/1059840510380206
8. Adam L. Hartman, Cynthia Di Laura Devore, and the SECTION ON NEUROLOGY, COUNCIL ON SCHOOL HEALTH, Peter B. Kang, Donald Gilbert, Andrea Gropman, Adam L. Hartman, Sucheta Joshi, Sonia Partap, Jeffrey Okamoto, Mandy Allison, Richard Ancona, Elliott Attisha, Cheryl De Pinto, Breena Holmes, Christopher Kjolhede, Marc Lerner, Mark Minier, Adrienne Weiss-Harrison, Thomas Young; Rescue Medicine for Epilepsy in Education Settings. *Pediatrics* January 2016; 137 (1): e20153876. 10.1542/peds.2015-3876

Further information and resources:

1. School nursing evidence-based practice clinical guideline: students with seizures and epilepsy. National Association of School Nurses. [Seizure-and-Epilepsy-Guidelines\\_NASN\\_2018.pdf \(ncesd.org\)](#)
2. Epilepsy in Schools | Healthy Schools | CDC. <https://www.cdc.gov/healthyschools/npao/epilepsy.htm>
3. School Health Epilepsy. <https://www.cdc.gov/epilepsy/pdfs/SchoolHealthProfilesBrief.pdf>
4. Managing Students with Seizures Program for School Nurses | Epilepsy Foundation. <https://www.epilepsy.com/living-epilepsy/our-training-and-education/seizure-training-school-nurses-caring-students>