

Written Testimony

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Mother, Child Advocate and Vice President for Communications for Michigan PTA
Before the Michigan House of Representatives Education
in SUPPORT of H.B. 5329 (Seizure Safe Schools Act)
Tuesday, June 18, 2024

Good morning, Chairman Koleszar, Vice Chairs, and members of the Committee. Thank you for this opportunity to speak before you today in support of House Bill 5329.

My name is Beth Hulett, and I proudly represent the Michigan Parent Teacher Association (PTA) as the Vice President for Communications. Aside from my role, I am the mother of two children who have experienced seizures in school. My daughter Hannah received her bachelor's degree this Spring and is beginning her master's degree this Fall. Tragically, my son, Brennan, died during a seizure on February 24, 2023, shortly after starting a welding program after his high school graduation. Their stories have inspired me to speak up for all students who encounter similar challenges.

As a parent, I've witnessed firsthand the impact of providing proper support for students with epilepsy.

My daughter, Hannah, had her first seizure in her preschool classroom at age three. Proper training could have helped the staff recognize she was having a seizure and to appropriately respond. Unfortunately, medical care and access to rescue medication were delayed for as much as 40 minutes. She remained in a seizure state for 10 hours, which put her at significant risk for brain damage or worse. Fortunately, after several years, Hannah no longer needed medication and has been seizure-free since that time.

The impact of a properly prepared school was evident when, fifteen years later, my son, Brennan, had his first seizure at age 16. It was thought to be a one-time occurrence brought on

by a new prescription, and although he started an anti-seizure medication as a precaution, we were caught off guard when he had a seizure in school less than a year later. His teacher recognized he was having a seizure and responded appropriately, turning him on his side, taking note of the length of the seizure, protecting his head, and that he hit his head when he fell to the floor. The school staff and administrators knew to clear Brennan's classroom and the halls for medical responders and had Brennan's school records in hand, including his seizure action plan, to pass on to them.

Seizure Action Plans are essential and tailored to each child's specific health concerns. An important aspect of my son's seizure action plan was that not every seizure would have required a trip to the emergency room. Instructions like this help mitigate potential embarrassment and trauma for the student and their peers while avoiding unnecessary medical expenses and lost academic time.

It's crucial to recognize the profound effects of epilepsy on learning, behavior, and physical and mental health. Brennan missed a significant amount of class time during his senior year of high school due to doctors' appointments, medication side effects, and anxiety. He sometimes felt uneasy being out of the house and essentially at the mercy of the world around him. In March of that year, he experienced another seizure that began in school. After that, he never returned to the building and graduated as a homebound student.

In 2022, Michigan PTA delegates passed a Resolution on Seizure Safe Schools, which is modeled after and in support of the work of the Epilepsy Foundation of Michigan. The resolution was later adopted nationally by PTA. By fostering collaboration between families, school staff, and healthcare providers when needed, we can create a safe, inclusive, and supportive environment for students with epilepsy.

It is my hope that no other child will have to face the same risks and challenges that my children did. As an advocate and a parent, I respectfully urge you to support House Bill 5329 for the health and safety of Michigan children living with a seizure disorder.

Thank you for your time and consideration.



Seizure Safe Schools

Whereas, Epilepsy is a disease or disorder of the brain which causes recurring seizures. The

National Epilepsy Foundation states that Epilepsy is the fourth most common neurological problem—only migraine, stroke, and Alzheimer's disease occur more frequently. There are many different types of seizures and varying levels of seizure control. Approximately one in 26 people will develop epilepsy at some point in their lifetime. At least 450,000-470,000 children are living with epilepsy in the United

States.

Whereas, A student living with a seizure disorder is more likely to have disrupted learning

caused by the effects of seizures and anti-seizure medication: disorientation, memory loss, loss of concentration, alterations in the student's behavior, fatigue,

headaches, and missed days of school.

Whereas, Many schools do not have a full-time nurse or other licensed healthcare professional

available to handle medical emergencies, and nursing care duties are often

performed by other school personnel.

Whereas, A Seizure Action Plan is an important tool that helps parents and schools partner to

keep children safe and healthy during the school day. Studies show that about one in 1,000 people with epilepsy die suddenly. A Seizure Action Plan is essential for preventing an emergency and informing others what to do when a student experiences a seizure. It is created specifically for each student's needs and includes instructions for administering any physician directed care, including seizure rescue medications which can help prevent death and injury to the brain and body, and also

decrease the risk of later cognitive difficulties.

Whereas, Greater awareness about seizure disorders is needed to help prevent seizures and

injuries, reduce stigma, and better connect people with a seizure disorder to the

care and support they need.

Whereas, The opportunity for academic success is increased when communities, schools,

families, and students work together to meet the needs of students with chronic health conditions and provide safe and supportive learning environments. Therefore

be it;

Resolved, That National PTA and its constituent organizations urge that all school personnel

receive general training on seizure recognition and response; be it further

Resolved, That National PTA and its constituent organizations urge that a Seizure Action Plan is

made part of the student's file for a student who experiences seizures and made available to all school personnel and volunteers responsible for the student; be it

further

Resolved, That National PTA and its constituent organizations urge that schools ensure

students living with a seizure disorder have access to FDA-approved medication

prescribed by the treating physician; be it further

Resolution: Seizure Safe Schools

Adopted: 2023

Resolved, That National PTA and its constituent organizations urge schools to bring seizure

awareness to the entire educational community so that students living with epilepsy or a seizure disorder can feel safe in school, reach their full academic potential, and

build meaningful friendships without fear of being stigmatized; be it further

Resolved, That this resolution shall be in full force and effect until the last day of June 2030.

Adopted: by the 2023 Convention delegates