

March 21, 2022

Representative Michelle Udall, Chair
Education Committee
Arizona State Capitol Complex
1700 W Washington St.
Phoenix, AZ 85007

Dear Chairwoman Udall and committee members:

The undersigned organizations write in support of SB 1654 and urge the Arizona legislature to swiftly pass this legislation. SB 1654 is critical to ensuring that students living with the epilepsies and seizure disorders in Arizona remain safe and are well supported in their school environment and have access to the care that they need.

Epilepsy is a medical condition characterized by seizures, which are sudden surges of electrical activity in the brain, that affects a variety of mental and physical functions. It is a spectrum disease comprised of many diagnoses including an ever-growing number of rare epilepsies. Approximately 1 and 26 Americans will develop epilepsy, and about 1 and 10 people may experience a seizure during their lifetime. There are approximately 470,000 people under age 18 living with the epilepsies in the U.S., including 11,200 children and teens in Arizona.

Seizures can happen in any place, at any time. According to the Centers for Disease Control and Prevention (CDC), approximately 336,000 kids have at least one seizure annually. Compared to students with other health concerns, a study from the CDC found that students 6-17 years of age living with the epilepsies were more likely to miss 11 or more days of school in the past year. Proper seizure first aid and continuity of care while children and youth are at school are necessary to ensure that students with the epilepsies remain safe and can reach their full potential with as minimal disruption to their learning as possible.

Arizona's Seizure Safe Schools bill, SB 1654 would greatly improve the care and safety of students with epilepsy and seizures in schools by:

- Allowing seizure action plans to be submitted for each student with a seizure disorder and made available to school personnel responsible for the student;
- Requiring school nurses and school personnel to undergo an approved seizure recognition and first-aid training course online;
- Ensuring the administration of FDA-approved medications by at least one trained school employee other than a school nurse; and
- Including a Good Samaritan Clause for those who act in good faith in accordance with the bill's provisions.

Our organizations support and have been involved with the nationwide initiative to pass Seizure Safe Schools legislation in all 50 states and the District of Columbia. So far, Seizure Safe Schools bills have been passed in the following 12 states: Kentucky, Indiana, Texas, Illinois, New Jersey, Virginia, Washington, Oklahoma, Nebraska, Alabama, Colorado and Minnesota. Additional states have laid and passed important groundwork towards this initiative.

We urge Arizona to become part of this momentum to properly protect and support the 11,200 students with the epilepsies as well as those who may experience their first seizure in the school setting by swiftly passing SB 1654.

Sincerely,

American Epilepsy Society
CACNA1A Foundation
CFC International
Child Neurology Foundation
CMCD Foundation
Coalition to Cure CHD2
CURE Epilepsy
CureSHANK
Danny Did Foundation
Dravet Syndrome Foundation
Dup15q Alliance
Epilepsy Foundation
Epilepsy Foundation Arizona
Hope for HIE
International Foundation for CDKL5 Research
Jordan's Guardian Angels
KCNQ2 Cure Alliance
KIF1A.ORG
Koolen-de Vries Syndrome Foundation
Lennox-Gastaut Syndrome (LGS) Foundation
Malan Syndrome Foundation
National Association of Epilepsy Centers
Paul's Purple Warriors
PCDH19 Alliance
Phelan-McDermid Syndrome Foundation
Rare Epilepsy Network (REN)
RASopathies Network
Ring14 USA
STXBP1 Foundation
SYNGAP1 Foundation
The Cute Syndrome Foundation
TSC Alliance