MISSOURI HOUSE OF REPRESENTATIVES

WITNESS APPEARANCE FORM

BILL NUMBER: **SB 710**	DATE: **4/13/2022**

COMMITTEE:
Downsizing State Government

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **ANDREW YOUNG**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL: **andrewrgyoung1993@gmail.com**	ATTENDANCE: **Written**	SUBMIT DATE: **4/12/2022 9:44 AM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

Many individuals in the state, men and women, boys and girls, parents and children, teachers and students, experience seizures. Whether it is happening to them or to someone near them, it is freighting as it happens. 1 out of 10 people will experience a seizure in their lifetime, and it can be severe. This can happen in a school setting, and it does every school year. This bill would help parents who have kids with epilepsy to be more at ease with their kids being in school and would give teachers and school staff the knowledge needed to respond to someone experiencing seizures. This will make schools more safe for everyone, and Missouri needs seizure safe schools.

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **ARNIE C."HONEST-ABE" DIENOFF-STATE PUBLIC ADVOCATE**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL: **arniedienoff@yahoo.com**	ATTENDANCE: **Written**	SUBMIT DATE: **4/13/2022 11:52 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

I am in Support of this Bill and Legislation to Protect Missouri Students and their Proper and Responsible Medical-Care.

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **CARLA DUVALL**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL: **carladuvall@sbcglobal.net**	ATTENDANCE: **Written**	SUBMIT DATE: **4/12/2022 5:22 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

Please get "Will's Law" to pass for better understanding what to do in case of seizures in school.

MISSOURI HOUSE OF REPRESENTATIVES

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TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **HEATHER M BEQUETTE**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL: **Heatherbequette@yahoo.com**	ATTENDANCE: **Written**	SUBMIT DATE: **4/12/2022 8:42 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

On May 26th, 2021, I witnessed what I would say was the scariest day in my life. Just completing my first year of teaching in a Rural Missouri school district in Southeast Missouri, I decided to work Summer School following this school year. There were roughly 60 students in the middle school building, with a total of three teachers in separate rooms. On the first day, after the morning classes were finished, we were on our way to the cafeteria gym for a break. All of the students in my class were exiting the room into a crowded hall with the other students as well. I was the last one to leave my classroom, when I noticed a student on the ground in the hallway. At first, I did not know what was happening. The student I noticed was one who I had been made aware of that can experience seizures. As they were on the ground, they were unresponsive, breathing heavy while gasping for air, and had uncontrollable body movements. There was only one nurse for the district during summer school, and she was visiting a different building at the time. The first thing I could do was have one of the students run to the office to notify the staff of what was happening. As the student was rushing to the office, I used my cell phone to contact the Assistant Principal, but was unable to get through to him. By this time, the office staff made it to where we were at and assessed the situation. After this, the staff member hurried to get the Assistant Principal. After about three minutes from the start of the seizure, the Assistant Principal was with us to take care of the child suffering from a seizure. We contacted 9-1-1, called the school nurse, and the child’s mother. As we were waiting for emergency response to arrive on the scene, we placed my cardigan under the student’s head and turned them to their side. Roughly seven minutes from the start of the seizure, the child’s mother arrived first, then the school nurse, and finally, the ambulance. In those seven minutes, I witnessed this student being unresponsive, breathing heavily, gasping for air, and not knowing what life would look like after this for the student. The child’s skin tone was changing to a purplish-blue, due to lack of oxygen. After this experience, I want to encourage ALL school personnel to be given training on what to do in this situation. I want to feel more prepared for IF this were to happen again. As I would also want to take this burden off of my students' parents knowing that if their child was to go through this at school, they would have trained personnel to care for their child until emergency services arrive.Thank you for your time, and please vote YES to pass Will's Law.

MISSOURI HOUSE OF REPRESENTATIVES

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TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

REGISTERED LOBBYIST:

WITNESS NAME: **HEIDI GEISBUHLER SUTHERLAND**	PHONE NUMBER: **573-636-5151**	
REPRESENTING: **MISSOURI STATE MEDICAL ASSOCIATION**	TITLE: **DIRECTOR OF GOVERNMENT RELATIONS**	
ADDRESS: **113 MADISON ST**		
CITY: **JEFFERSON CITY**	STATE: **MO**	ZIP: **65101**
EMAIL: **heidi@msma.org**	ATTENDANCE: **In-Person**	SUBMIT DATE: **4/13/2022 8:52 AM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

MISSOURI HOUSE OF REPRESENTATIVES

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Downsizing State Government

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WITNESS NAME

BUSINESS/ORGANIZATION:

WITNESS NAME: **HOLLY BRADY**	PHONE NUMBER: **816-489-2220**	
BUSINESS/ORGANIZATION NAME: **PURPLE PEACE FOUNDATION**	TITLE: **FOUNDER/PRESIDENT**	
ADDRESS: **455 SW EAGLES PKWY #4108**		
CITY: **GRAIN VALLEY**	STATE: **MO**	ZIP: **64029**
EMAIL: **holly@PurplePeaceFoundation.org**	ATTENDANCE: **In-Person**	SUBMIT DATE: **4/11/2022 10:46 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

I will testify in support of SB 710 for seizure safe schools in Missouri. I will represent Purple Peace Foundation and speak on the benefits this law will have for students who are living with epilepsy and seizure disorders.I also have experience as an elementary teacher for 17 years, so I understand the impact this bill will have for students and teachers. Lastly, I will speak on behalf of my daughter, Amanda Brady, who died from a seizure in 2011 at the age of 13.

MISSOURI HOUSE OF REPRESENTATIVES

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COMMITTEE: **Downsizing State Government**		

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **KAYCI CAPPS**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL: **kaycicapps@gmail.com**	ATTENDANCE: **Written**	SUBMIT DATE: **4/12/2022 12:13 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

Good morning. My name is Kayci Capps and this act is named after my 4-year-old son, William “Will”. I would like to begin by thanking you all for hearing my testimony today and send my deep regrets that we are unable to attend in person.Will was born a perfectly healthy baby in November 2017. At 3 months old on February 22, 2018, he had his very first seizure. I watched EMS pack up my small baby and take him to the military hospital close to where my husband, Will’s father, was stationed at the time with the Air Force. He was seen by the top child neurologist in the USAF and it was deemed that this was more than likely an atypical representation of baby reflexes and not an actual seizure and he should soon be totally cleared by neurology. Two weeks later, Will had an undeniable seizure lasting close to 3 hours, requiring him to be intubated. After this, Will had genetic testing where we first heard the term “Dravet Syndrome”. Dravet Syndrome is a rare, catastrophic form of epilepsy affecting approximately 1 in 20,000. In addition to seizures, it is characterized by both physical and cognitive delays. It starts within the first year of life and is one of if not the most difficult type of epilepsy to treat. Will has failed almost every epilepsy treatment on the market and continues to have countless seizures of different types every single day. He has been intubated a dozen types for seizures that would not stop and we have lost track of the number of hospitalizations he has endured in his 3 years of life. He also had a surgery at 2 years old for an implant called a Vagus Nerve Stimulator, which is implanted in his small chest to help curtail some of his seizures and works as a rescue treatment as well. Because of his daily seizures, we carry rescue medicine with us everywhere we go. Anywhere Will goes, his rescue bag is with us in the event we need to intervene for his seizure types including clusters or a seizure that won’t stop and would lead to further brain damage. We use this bag about 4 times a week on the conservative side. As we got closer to the time for him to start preschool when he turned 3 and aged out of the home-based Missouri First Steps Program, we started to worry about how this would affect his future and school career. How would he be able to attend any school setting with daily, uncontrolled seizures? How could we feel comfortable sending him and giving him some semblance of normal 4-year-old life, going to school and making friends?As the time approached, we met with the school team to prepare for him to begin in a special education setting. We shared our concerns that we were scared for him to attend school and be away from us for the first time.His team expressed the same concerns, especially with only one school nurse on duty who had obligations to other students in the building and could not feasibly be readily available when Will inevitably started seizing. No one else in the building had ever been trained on dealing with seizures or any type of seizure protocol. If Will’s private duty nurse calls out, 9 times out of 10 Will has to miss school because no one else is trained in seizure protocol and school becomes a danger to him and he misses out on the opportunity for a free and equal education. For most parents, starting school is filled with excitement of watching your child become more independent, grow, learn, and make first friends. For us, it was filled with anxiety and figuring out how best to prepare his team for his complex medical needs. Time and time

again I was asked what his seizures looked like. The caveat with Dravet Syndrome is that he has every type of seizure out there. Some are as subtle as staring to one side or twitching of the extremities, which appear small but can be as dangerous as the obvious seizures we see on television. Would Will start to subtly seize and it go unnoticed or be brushed off by the untrained eye until it was too late and the seizure was unable to stop at that point and he would be intubated yet again? These are some of my fears for my 4-year-old son every single day. Two years ago, we began to look into seizure safe school legislation as we were concerned not only for our son Will, but all students and staff in Missouri living with seizures and epilepsy. Currently, there are only fifteen states in the country that have laws to protect children who have seizures during the school day. It is our hope that Missouri will be the next state to train teachers and school staff in seizure recognition and first aid.By enacting this critical legislation, Missouri would be protecting almost 8,300 children (ages 0-17) with epilepsy in the state, not to mention those who may have a single seizure while attending school. If Senate Bill 710 becomes Will's Law, over 16,000 Missouri parents including myself and my husband would sleep better every night knowing that our children are as safe as possible at school under any staff present.In addition to being Will's mother, I am also his voice as he is nonverbal. It is my responsibility to him to keep persevering and reaching out to people like yourselves to make his world a little safer and give him any sense of normalcy that I possibly can. 20% of children with Dravet Syndrome do not make it past their school age years, not to mention the children out there with other forms of epilepsy who will also not live to see adulthood due to seizures and their complications. Seizures are both life threatening and potentially brain damaging if there is not proper intervention in a timely manner. Passing this bill would ensure adequate training is provided and will make our schools seizure safe and protect children like my Will. I urge you to please support and vote yes on Will's Law which will make a world of difference for our children. Thank you.

MISSOURI HOUSE OF REPRESENTATIVES

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TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

BUSINESS/ORGANIZATION:

WITNESS NAME: **LAURA ROESELER**	PHONE NUMBER: **314-807-9212**	
BUSINESS/ORGANIZATION NAME: **EPILEPSY FOUNDATION OF MISSOURI AND KANSAS**	TITLE: **CHIEF EXECUTIVE OFFICER**	
ADDRESS: **222 S. MERAMEC AVE, SUITE 202-1050**		
CITY: **ST. LOUIS**	STATE: **MO**	ZIP: **63105**
EMAIL: **lroeseler@efmk.org**	ATTENDANCE: **Written**	SUBMIT DATE: **4/12/2022 5:01 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

My name is Laura Roeseler and I am the Chief Executive Officer for the Epilepsy Foundation of Missouri and Kansas and a resident of St. Louis County, MO. The Epilepsy Foundation fully supports Senate Bill 710 which would improve the care of students with epilepsy and seizure disorders in Missouri schools. We recognize the need for all schools in Missouri to have individualized health care plans relating to a student's epilepsy or seizure disorder and training for all school employees around epilepsy education and seizure first-aid. In 2019, the Missouri Department of Elementary and Secondary Education stated that 349 school districts reported 7,144 students with a seizure disorder. 133 school districts, representing 128,653 students, did not report. We know that 1 in 10 people will have an isolated seizure incident at some point in their lifetime, which presents the possibility of an additional 12,865 students impacted by seizures in Missouri. It is critical that schools are well-equipped with the tools necessary to provide a safe and enriching environment for students with epilepsy. The thousands of children living with the epilepsies in Missouri are counting on your support. Thank you for the opportunity to provide this written testimony and for all that you do for our community!

MISSOURI HOUSE OF REPRESENTATIVES

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WITNESS NAME

BUSINESS/ORGANIZATION:

WITNESS NAME: **LAURA THRALL**	PHONE NUMBER: **301-918-3784**	
BUSINESS/ORGANIZATION NAME: **EPILEPSY FOUNDATION**	TITLE: **PRESIDENT & CEO**	
ADDRESS:		
CITY: **BOWIE**	STATE: **MD**	ZIP: **20716**
EMAIL: **dbrown@efa.org**	ATTENDANCE: **Written**	SUBMIT DATE: **4/12/2022 4:24 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

The Epilepsy Foundation are pleased to endorse SB 710, also known as Will’s Law. This bill supports a critical priority for the Epilepsy Foundation and the epilepsy community writ large – safety and continuity of care in the event of a seizure at school. Through this bill, school personnel will be required to take a training every two years in the care of students with epilepsy and seizure disorders. This will ensure they are not only prepared for but can recognize and respond appropriately and efficiently to a student experiencing a seizure. The legislation would also support the use of an Individualized health care plan and emergency plan which will further ensure that school personnel have access to information that may be specific or unique to that student. Taken together, the provision in the bill represents important protections necessary to make certain that students living with epilepsy are safe while attending school or a school-related function.The Epilepsy Foundation is the leading national voluntary health organization that speaks on behalf of the at least 3.4 million Americans with epilepsy and seizures. Our local affiliate, Epilepsy Foundation Missouri & Kansas, provides services and advocates on behalf of the 61,200 Missourians, including 8,300 children, living with epilepsy and seizures in the state. Together, we foster the wellbeing of children and adults affected by seizures through research programs, educational activities, advocacy, and direct services. 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. Approximately 1 in 26 Americans will develop epilepsy, and approximately 1 in 10 people will experience a seizure, at some point in their lifetime. A seizure can happen to any person, in any place, at any time, and it is vital that school personnel are prepared to respond in this event appropriately and effectively. Compared to students with other health concerns, one Centers for Disease Control and Prevention study showed that students aged 6-17 years living with epilepsy were more likely to miss 11 or more days of school in the past year. For these students, proper seizure first aid and continuity of care while they are at school is crucial to ensuring they can reach their full potential with as minimal disruption to their learning environment as possible.The Epilepsy Foundation is proud to endorse this important legislation to help ensure children living with epilepsy and seizures are safe and experience continuity of care while at school. Together, we can make sure Missouri is at the forefront of this important nationwide initiative by joining the 14 other states that have passed these critical protections. Please feel free to contact Dominique Brown, Senior Manager, State Relations and Public Policy, Epilepsy Foundation at dbrown@efa.org with any questions or follow-up.

MISSOURI HOUSE OF REPRESENTATIVES

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **SHANNON WALTER**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL: **scolledge59@gmail.com**	ATTENDANCE: **In-Person**	SUBMIT DATE: **4/12/2022 11:37 AM**

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Speaking from a parent’s perspective for the experience with the school my son attended.

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **STACEY PERRY**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL: **avonrepstacey@yahoo.com**	ATTENDANCE: **Written**	SUBMIT DATE: **4/12/2022 11:43 AM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

I am an adult living with epilepsy who experienced difficulties in school and continue to work with children who encounter school staff who do not know how to deal with seizures.

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **SUSAN GIBSON**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL: **Onesuegibson@protonmail.com**	ATTENDANCE: **Written**	SUBMIT DATE: **4/12/2022 2:34 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

MISSOURI HOUSE OF REPRESENTATIVES

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Downsizing State Government

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WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **TINA GATES**	PHONE NUMBER:	
BUSINESS/ORGANIZATION NAME:	TITLE:	
ADDRESS:		
CITY:	STATE:	ZIP:
EMAIL: **tinalgates53@gmail.com**	ATTENDANCE: **Written**	SUBMIT DATE: **4/12/2022 2:11 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

VOTE YES!!!!! For my epilepsy warrior and so many others like him in Missouri! My son was diagnosed with epilepsy in 2017, when he was in Jr High School. He has had several seizures at school and majority of the time in the presence of teachers who didn't know how to respond or react. By the time the nurse arrived to the class, the seizures were over and the nurse would walk him to the clinic. I think it is absolutely critical that every employee in the school know seizure safety and what to do and NOT to do.

MISSOURI HOUSE OF REPRESENTATIVES

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Downsizing State Government

TESTIFYING: ☑ IN SUPPORT OF ☐ IN OPPOSITION TO ☐ FOR INFORMATIONAL PURPOSES

WITNESS NAME

INDIVIDUAL:

WITNESS NAME: **VICTORIA I HODGES**	PHONE NUMBER:
BUSINESS/ORGANIZATION NAME:	TITLE:

ADDRESS:

CITY:	STATE:	ZIP:
EMAIL: **skeetvicki@yahoo.com**	ATTENDANCE: **Written**	SUBMIT DATE: **4/12/2022 3:37 PM**

THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.

I support this bill in it's entirety. As a parent of a child with refractory generalized epilepsy who has suffered hundreds of absence seizures and 1 tonic clonic seizure while at school it is imperative that all school personnel know how to give first aid to a child/ staff member in the event of a seizure occuring. At the present time I send links to all of my daughter's teachers to become certified in seizure first aid, but it is up to them to actually take the course. Last year, my daughter suffered from a status absence seizure that led to a tonic clonic seizure at school. Staff recalled that event as being chaotic and uncertain. I have no doubt that if all school personnel has received proper training on how to deliver seizure first aid my daughter's care would have been more streamlined until EMS had arrived. The school did the best they could with the resources they had, but in my heart I know things could have ran smoother with proper education and training on how to care for a student when having a seizure. Until this bill is passed I will continue to advocate for all those living with epilepsy and for seizure first aid to be required for all school personnel.