Subject: Testimony in Support of Seizure Safe Schools Legislation
Hearing Date: Monday March 31, 2025
Submission Date: Wednesday March 26, 2025

Dear Members of the Maine Committee on Education and Cultural Affairs,

My name is Emily Thompson and I live in North Yarmouth. I live with my husband, my 5-year-old son Griffin who lives with epilepsy, and our 2-year-old daughter Josie.
I am submitting this testimony as an Epilepsy Foundation New England volunteer advocate, and as a mom, who will do anything for her children.

Griffin was just over three and a half when he was diagnosed with Epilepsy, two days after his baby sister was born. For those who don't know, Epilepsy is a disorder of the brain where there are electrical abnormalities that cause various types of seizures.

Griffin's story started out at day care on a Friday afternoon. He had an unwitnessed fall off the picnic table, lost consciousness and was "foaming at the mouth." I was 20 minutes away, almost 41 weeks pregnant, in complete panic. The paramedic asked over the phone if it was ok for them to take him to the hospital, to which I breathlessly agreed. He was treated for what we thought to be a concussion and we were discharged later that day as he returned to his baseline within a few hours. Five days later, two days after our daughter was born, he had a tonic-clonic seizure in our living room. As soon as I saw this, I realized that he hadn't had a concussion at daycare the week before as we initially thought, it was his first tonic-clonic seizure. We were back in an ambulance to Maine medical center. That day changed our lives forever, he was diagnosed with epilepsy on March 29, 2023. We learned from the neurologist that day in the ER, someone gets a diagnosis of epilepsy when someone has two unprovoked seizures.

Griffin's seizures started to come fast and furious over the course of 12 weeks from the date of his diagnosis. The tonic-clonic seizures would cause him to yell out, fall down, lose consciousness and shake uncontrollably. His arms and legs would become stiff. This would last anywhere from a minute to 3 minutes – each second we counted out loud to know if we would reach the time to give him his rectal rescue medication, traumatizing for everyone. And if you're wondering why rescue medication has to be given rectally, is because he is under the age of 6 when a nasal option is approved. These raw details are hard to hear, but even harder to have to live through and witness. We would watch over him praying, counting, hoping for it to stop and for our sweet boy to come out of it and start breathing again. Over the course of 12 weeks, he suffered almost 30 tonic-clonic seizures. He has a permanent goose egg on his head from falling into the bookshelf or TV stand when my husband or I weren't able to catch him in time, remembering we had a newborn at home that was right by our sides. Griffin also started to develop myoclonic seizures, which are jerking and twitches in his face and arms and sometimes his vocal cords, he would make odd noises that would tip us off that another tonic-clonic seizure may be coming. He also developed absence seizures where he would stare into space, completely loosing connection with us or anything going on around him. His sweet small face just staring off into the distance. As elated as I was for my new baby, my heart was absolutely being crushed to pieces watching my boy be so ill, I felt helpless.

Griffin went through multiple medications with no relief. Finally, in June 2023, after back-to-back tonic-clonc seizures and almost continuous absence seizures, we landed back in Barbara Bush Children's Hospital. We changed our medication routine and started the modified atkins diet, a version of the ketogenic diet that has been proven efficacious for seizure control. Over time, we did achieve seizure freedom, but not without further challenges. We ended up at Barbara Bush Children's Hospital in the pediatric ICU for Depakote toxicity. A drug often used for bipolar disorder, but also epilepsy. He laid limp in the ICU bed hardly interacting. His liver function tests were far from normal, he was at risk for infection and bleeding because the drugs hurt his bone marrow. After time, weaning off these meds and switching course again, we remained seizure free on a new drug regimen.

My son now is amazing. He plays hockey, t ball, he loves the ninja turtles and super hero's and he absolutely adores his little sister. You would never know looking at him that he has this dark unhealthy past, he is completely developmentally normal and happy. But, not a day goes by that I don't think about epilepsy and worry about him. I have my phone with me at all times, and an apple I watch that will alert me if his teacher's text or call. It is a constant thought in my mind all the time.

The day of his first seizure, his teachers at day care, not prepared to handle seizures, acted with haste and courage and called 911 and did the right thing. I was desperate to keep life normal for him so on his good days, I would send him to daycare. He needed to be with his friends and continue to learn. We all know the importance of early childhood education and I felt so strongly that he shouldn't be kept at home just watching and waiting and missing out on life. His teachers were amazing. They worked with us to know signs of impending seizures, to know what to do if he had one and how to administer his rescue medication should that happen. They went into this newfound relationship with my family with minimal hesitation. The epilepsy foundation of new England was amazing in helping us navigate this course with them. They provided education and training to the teachers about epilepsy and seizure disorders. I wouldn't have survived that first year without the epilepsy foundation of new England and the support they gave my family and the teachers at his daycare.

His teachers at daycare know him so well, and I have felt the utmost confidence in dropping him off there every single day. This coming fall he will be entering kindergarten at a new school in another town. We will discuss an IEP or a 504 plan, hopefully, as he has side effects from his medications that impact him at various times. He will have all new teachers who I will have to learn and establish trust to watch over and be able to help my sweet boy, should we lose our seizure freedom. I'm asking, begging, that this law gets put into place to educate people on seizure safety and awareness. To have teachers and staff be able to recognize and react to a seizure can be life-saving. When I think about my son, laying in my arms, sometimes turning blue because he hadn't started to breathe yet, it makes me sick to my stomach thinking that could happen again in a setting where the people around him may not know what to do.

Please consider Griffin, and all of the other children in Maine who have been cursed with this horrible illness, and in Griffin's case, for no identifiable reason.

These children are our future, now more than ever, and we have to take care of them. Teaching seizure safety and seizure awareness is what they deserve. Please, please protect our children.

Sincerely,

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