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Testimony in Support of LD 211 (HP 134)

Kristine Binette, Parent & Community Education Manager, Epilepsy Foundation New England

To The Maine Committee on Education and Cultural Affairs:

Three minutes. 180 seconds. That is the time you have to administer life-saving seizure rescue medication before my daughter's seizure could escalate into something far more dangerous.

Now, imagine being told that your child—your son or daughter—might not receive that medication in school simply because a nurse isn't available. Imagine being told that the only way your child can go on a field trip is if you, the parent, stay just steps away. Imagine knowing that the medication, the one that could stop the seizure, is right there—within reach—but won't be given because the right person isn't there to administer it.

What if I told you that your child's safety depends not on medical science, not on a doctor's orders, but on outdated policies? That an FDA-approved medication, designed specifically for non-medical personnel to administer, is still being withheld from children who need it?

This is not hypothetical. This is my reality. This is the reality for families across Maine.

My name is Kristine Binette. I am the mother of a 17-year-old daughter with epilepsy, I live in Cumberland County, and I serve as the Community Education Manager for the Epilepsy Foundation New England. I am here today in strong support of LD 211 (HP 134), "An Act to Make School Safer for Students with Epilepsy and Other Seizure Disorders by Requiring Seizure Action Plans and Training in Schools."

No family should have to choose between sending their child to school—knowing they may not receive the care they need—or keeping them home, isolated from their peers and education. No child should be denied access to life-saving medication simply because a nurse isn't present.

Anything over five minutes is considered a seizure medical emergency known as status epilepticus. Seizure rescue medications are often administered before the five-minute mark because we know that the longer a seizure lasts, the harder it is to stop.

Not only do I see this impact on my own daughter, but I witness it in the lives of other families, and I hear it from the physicians who care for them. In my role, I have personally trained over 636 school staff in seizure first aid across Maine. I have been approached by

teachers, physicians, and school nurses—all asking for help to support the delegation of rescue medication administration.

We also have an obligation to ensure that the staff working with our children are properly trained to help them during a seizure. School nurses play a vital role, but we know they are stretched thin, often covering multiple schools in a district. They are also parents themselves, with their own families to care for. They cannot be everywhere at once. They, too, deserve support in their roles.

Allowing Maine schools to continue operating without protections for children with epilepsy is unacceptable. Every day, I drop my child off at school and wonder if her safety will be in jeopardy. I wonder if her Seizure Action Plan will be followed. I wonder if she will receive the medication she so desperately needs in time to save her.

Three minutes. 180 seconds. That's all it takes to save a life. Let's make sure that time isn't wasted.

I urge you to support LD 211. Thank you.

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