

Written Testimony of

Victoria Ross

Mother of Emmett Frederick Ross

Westport, CT

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Public Health Committee

**Raised Bill No. 369 – An Act Concerning Authorization For The Use of Feeding Tubes and Antiepileptic Medications In School Settings**

My name is Victoria Ross and I am the mother of Emmett Ross who has suffered from epilepsy since he was a baby. Emmett is 6 and currently goes to St Vincent's special needs school and rides a bus to and from without a person on the bus who is allowed to administer Diastat at the onset of a seizure. Emmett's current seizures do not resolve themselves and always need the intervention of Diastat to stop them. The longer he goes without the Diastat, the harder it is to stop the seizure and could catapult him into state of continuous seizure which could kill him. The consequences of this happening are unthinkable given that the medication that could prevent this is along side him in his back pack.

If the current protocol is followed when the seizure starts, the bus driver is notified by the aide, the bus pulls over, they call 911, they wait for EMS to arrive (all while Emmett is suffering), EMS assess the situation, calls the hospital for an order from a doctor to place an IV into Emmett, which usually take several attempts, then can administer another medicine called Ativan to stop the seizure. This all takes a great deal of time and there is no saying if it will be in time to save my sons life.

Emmett has had two episodes involving the bus this year. The first occurred when the bus driver and aid were transporting Emmett from school to the bus when the seizure started. He was brought back into the school where the school Nurse could help him. The second time the bus was arriving at school when the seizure started and the school nurse was available to administer Diastat. Both the bus driver and the aide came to me asking what they could do to help Emmett if this happens in transit. They want to help him, but I am not allowed to show them how they could potentially save Emmett's life.

Diastat comes in a pre-loaded syringe and has a flexible plastic applicator that is easy to use and there is no risk of physical harm or overdose. The only harm that could come to my son is by not giving him the Diastat.

Emmett's seizures have no rhyme or reason as to when one is going to occur.

Emmett often cries out and grasps his head at their onset. Emmett's body trembles, his heart rate jumps and his breathing becomes shallow as his muscles convulse. These seizures are extremely painful, scary and increasingly dangerous the longer they last. We must make sure that this emergency medication is allowed to be administered at any time by someone who is with him.

Thank you.