

Written Testimony of
Ron Lamontagne
Parent of a child living with Epilepsy
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Joint Committee on Children

Raised Bill No. 5303 - AN ACT CONCERNING ACCESS TO EMERGENCY MEDICINE FOR CHILDREN WITH EPILEPSY

Good morning Senator Bartolomeo, Representative Urban, and members of the Joint Committee on Children. Thank you for the chance to speak in support of this important Bill.

My name is Ron Lamontagne and I live in East Berlin. I am an Epilepsy Foundation of Connecticut Board member, volunteer, Epilepsy Awareness Advocate and most importantly the father of 8 year old Kollin. I would like to thank you for allowing me to speak in support of Raised Bill No. 5303.

My son Kollin was diagnosed with Epilepsy a little over 4 years ago when he had his first seizure during a nap at daycare at the age of four. His seizure diagnosis is Partial onset with secondary generalized seizures. His disorder can cause anything from a slight twitch and confusion to Tonic-clonic seizures. Since that time, he has endured many seizures, some of which required the use of emergency anti-epileptic medications to stop his seizures. My son's prescribed emergency medication accompanies Kollin wherever he goes, to school, to camp, to friend's houses, and of course is always on hand for a trip to the store or a Sunday drive. It is to be administered if his seizure last 5 minutes or longer. Five minutes may not seem like a long time to some, but to a parent watching their child convulse uncontrollably it is indeed an eternity. His rescue medication is what can not only stop his seizure but is also what will stop his young brain from having potential damage and can save his life.

I am not nearly as knowledgeable as a school nurse, but according to the current laws I am considered more capable of administering this medication than the average school teacher, Paraprofessional or other competent school staff. I understand that anyone that administers emergency medications for seizures should be educated and properly trained. However, in a school day there are many people who I trust to care for my child, only one of them being the school nurse.

The fact that the only permitted person to administer emergency anti-epileptic medications are nurses creates obstacles for both me as a parent and for the schools themselves. Any after school or off grounds activities create scheduling issues to make sure a nurse will be available to accompany my son just in case of emergency. Additionally in my son's school there have been at least two other children known to have seizures attending at the same time as him. If my son needs to go off grounds, should I take the nurse away from these two other children who also might need exactly what he needs? These are just three children in a school of 200. Should the only school nurse also be taken away from 200 other children who may need her services just to meet the stipulations of the law?

The new language in Raised Bill No. 5303 is much more manageable. Anyone authorized to administer emergency anti-epileptic medications should be properly trained and will be utilized if the School Nurse is not available in a timely manner, but there are many people in a school setting who are capable of this ability. These same people are trusted to administer Epi-pens, and observe students with diabetes in case of trouble. Cannot the same people be trusted to administer a pre-dosed medication in an emergency, just as a parent can? I have no special training, and yet the doctors felt comfortable with sending me off with verbal instructions on how to administer the medication after my son's first seizures. I personally have instructed extended family including my oldest son who was 13 when his little brother had his first seizure on how to save Kollin's life.

Thank you for your thoughtful consideration and introduction of this important legislation. I sincerely appreciate your time and for allowing me to testify.