

Testimony in favor of HB 5303

My name is Jim Ross and I am the father of Emmett Ross, an 8 year old with Epilepsy whose story has helped create this bill to increase the protections for children with Epilepsy. Emmett was diagnosed when he was 1 year old with Epilepsy. Like most children with Epilepsy, Emmett's seizures can happen anywhere and at any time. When the seizures occur, they are paralyzing, frightening and very painful for him, they inhibit his breathing and are not self-correcting. In short, without emergency seizure medication, Emmett's seizures are very life-threatening.

Prescribed and pre-filled, emergency anti-seizure medication is our best and quickest defense against a seizure. Within a minute or two after administering the emergency medication, Emmett's seizure releases and his body relaxes with a thankful sigh. My wife and I (and family) have administered Diastat, an emergency anti-seizure medication, hundreds of times. It is simple to administer and it has been effective every time.

This legislation closes a dangerous emergency care "coverage" gap during school that exists when a school nurse is not immediately available. No one other than the school nurse can administer emergency medication to a child stricken with a seizure....but what happens if they are not available? This bill is simple common sense....when a nurse is not immediately available then a trained, non-medical school personnel can step in and administer the emergency medication in the nurse's absence. This does not replace the nurse but provides an essential back-up in case the nurse is not available.

This is the same approach already in practice in CT schools for children with severe allergic reactions. (Not surprisingly, many other states like Kentucky, Tennessee, Oregon and California have similar emergency medication provisions for trained, non-medical school personnel to administer the Epi-Pen (Epinephrine), Diastat and Glucagon in emergency situations.) This CT bill reflects a national concern and awareness for Epilepsy emergency care for children in schools.

I would like to also address some of the concerns and opposition to this bill made single-handedly by the school nurse community and their lobbyist organizations. They do not deny the emergency nature of a seizure nor the importance of timely administration of the anti-seizure medication.

Today, school nurses with direction from the parents and the child's physician in a child's emergency care plan maintain and administer the child's plan which includes the use of Diastat in the school setting. And school nurses are having to use it....by the data collected in the CT State Department of Education's 2011 "Health Services Program Information Survey Report", Diastat is the 2nd most actively utilized emergency medication in CT schools after the Epi-Pen. (The link for the report is [CT Health Services Program Information Survey Report 2011](#)) Another important highlight in this report is that about 20% of CT public/private schools have less than one nurse for every 750 students which leads us back to the issue at hand: Seizures are common and there

is no guarantee that a nurse will be available. Children with Epilepsy need to have a back up....because their lives(not the nurse's jobs) depend on it. Why must we even debate this?

A few final points regarding opposition to this life-saving legislation for children with Epilepsy. The nurses claim that their licensing credentials and professional expertise make them singularly qualified to identify and deal with the complexities of a seizure. Unfortunately for the child suffering a seizure, all their licensing and expert experience amounts to NOTHING if they are not immediately available to administer the anti-seizure medication. The administration of the medication has been crafted specifically for emergency situations and for non-medical person administration because it is more important THAT the medication is administered quickly than WHO administers it.

As grateful as we are to school nurses who manage our children's individual emergency care plan and rush to our children's side when they are stricken, the reality is that with all their qualified experience, licensing and medical expertise, they can never be certain that they will be available. No school nurse can be on every bus, every field trip, every athletic event or every school building or foresee every emergency situation. It is not fiscally prudent for school districts to hire so many nurses (nor is it necessary) nor is it logistically possible.

Finally, nurses claim that seizures are complex and present differently in different children. The fact is thought, that today nurses rely on teachers, coaches and paraprofessionals to alert them when a seizure emergency occurs....after all who calls the nurse when a situation arises? Does it not make even more sense to train and educate non-medical school personnel so that they can be better informed and capable to respond? They are our child's "first responders"....let's give them the training and permission to step in when a nurse is not available to protect our children's lives.

This bill is not only common sense. It is literally and figuratively about Time for this legislation to be enacted...time is the key in administering emergency seizure medication to save a child's life and time is critical in getting this legislation passed. Each day that goes by without this protection is another day we ask these children with Epilepsy to completely bear the burden of our indecision....and it is too dear a price for them to pay. Do not wait...do not hesitate...our children's lives depend on it.

Sincerely,  
Jim Ross  
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## Testimony in Favor of HB 5303 from James Ross

**In the subject line:** HB 5303 (Emergency Medication for Children with Epilepsy)

**In Email text:** Copy and Paste one of the three options below(or write your own).

**For the electronic record, I am writing in support of HB 5303.** I want to make sure that children with Epilepsy have timely access to emergency seizure medication when they have a seizure at school. Protecting a child's life should always be paramount so please support this bill into law.

**For the electronic record, I am writing in support of HB 5303.** Seizures can happen anywhere and at anytime. We must take action to protect children with Epilepsy who can not protect themselves. This bill closes the emergency care "gap" that exists today when a school nurse is, for any reason, not immediately available and there is a willing and trained teacher, coach or paraprofessional ready to help. Let's take care of these children by supporting this bill into law today!

**For the electronic record, I am writing in support of HB 5303.** Similar to a life-threatening food allergy, seizures represent life-threatening emergency events that must be treated as quickly as possible. And like life-threatening food allergies, there is a swift, pre-filled and physician prescribed antidote to save the child from harm if administered quickly. .And both are part of a parent-approved individual emergency care plan for their child. But **unlike** life-threatening food allergies where trained non-medical school personnel are allowed to step in to administer Epinephrin using the Epi-Pen, they are not allowed to administer Diastat to a stricken child in the dangerous grasp of a seizure. This is not acceptable. Please support this bill into law!

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Please take a brief moment to send a note..Our son, Emmett, and thousands of other CT school children with Epilepsy, will breathe a sigh of relief when you do (this is what actually happens to a child in the throes of a seizure a minute or two after the emergency seizure medication has been administrated...thus breaking the seizure.) This bill and the medication is a life-saver.

Thanks for helping.....Cheers