



## STRONGER TOGETHER

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March 3, 2014

State Senator Danté Bartolomeo, Co-Chair  
State Representative Diana S. Urban, Co-Chair  
Joint Committee on Children  
Room 011, Capitol Building  
Hartford, CT 06106

Dear Co-Chairs Bartolomeo and Urban,

On behalf of the more than 60,000 people living with epilepsy in Connecticut, the Epilepsy Foundation, and our local affiliate, the Epilepsy Foundation of Connecticut, we ask you to support RB 5303, legislation that would permit any trained, non-medical personnel to administer Food and Drug Administration (FDA) approved emergency medication for seizures. RB 5303 would ensure children living with epilepsy have appropriate and timely access to life saving emergency seizure medication and access to the full range of school and related experiences.

RB 5303 would permit any trained, non-medical personnel to administer FDA approved emergency medication in the rare circumstances that a child may be having life-threatening cluster seizures. Emergency seizure medication with predetermined dosing requires no medical intervention and its use can help prevent more serious and life-threatening events from occurring.

The Epilepsy Foundation is most concerned by assertions that only medically licensed personnel can administer this medication, which often results in children not having access to the full range of school and school-related experiences in the least restrictive environment because the child has a type of seizure for which emergency seizure medication may be needed. We are aware of multiple situations in which children with epilepsy who need access to emergency seizure medication have been denied access to school or school-related activities, or have incurred unnecessary medical risks because educators and child care service providers refuse to make the medications readily available on-site. Children have unnecessarily been excluded from such programs because some individuals have mistakenly asserted that these treatments must be administered or applied by a medical professional, or that extensive monitoring of the child is required. Delaying immediate treatment with a readily available emergency medication prescribed for a child experiencing a seizure can be life-threatening. Additionally, the child's family may incur significant expenses (ambulance rides, emergency room and doctor visits, etc.) when 911, or other emergency responders, are called instead of trained personnel administering emergency seizure medication on-site in a timely manner.

The FDA has approved the use of emergency seizure medication as safe and effective to be administered by non-medical caregivers who have been instructed to use it, including parents, caregivers, or school personnel in accordance with the child's treatment plan. The Epilepsy Foundation's Professional Advisory Board, comprised of clinicians, scientists and other professionals with expertise and interest in seizure disorders, and other medical experts in the treatment of epilepsy in children, agree that trained, non-medical personnel can safely administer emergency seizure medication. Therefore lack of access to a full-time nurse on-site is not an acceptable reason to refuse to administer the medication or to deny a child or student access to the program.

For most people, conventional medications that can be taken orally are effective in controlling seizures. But some children are susceptible to prolonged, cluster, or status seizures, which may last longer than five minutes in duration and can cause serious injury and even death. For these children, a physician may prescribe emergency seizure medication to be administered on an emergency basis. Following standard procedures, as prescribed by the treating physician, it is crucial that caretakers administer emergency seizure medication in a timely manner when a prolonged seizure or cluster of seizures occurs.

The Epilepsy Foundation urges providers of childcare and educational services to work with the child, his or her parents, and the child's treating physician to develop a seizure treatment plan for all children with epilepsy, including those who may, at times, require emergency seizure medication. Schools and service providers who develop this plan should also, with the family's input, designate a staff person in the school to implement the plan if necessary. Such a plan may be a part of a Section 504 plan, an Individual Health Plan (IHP), an Individualized Education Program (IEP), or simply a plan required to ensure the schools' compliance with the Americans with Disabilities Act (ADA). The critical point is that a mutually satisfactory approach that allows the child or student complete access to educational opportunities can and should be developed to cover the potential, usually very rare need for the administration of emergency seizure medication.

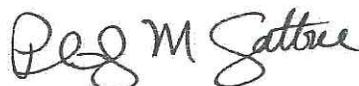
Access to emergency medication in all public schools and school activities is not uncommon in other states in the country, and a number of states have passed laws clarifying that emergency seizure medications should also be available in private schools. Studies make clear, and medical experts in epilepsy agree, that the use of emergency seizure medication by non-medical personnel can be done safely and effectively, and can be life saving.

The Epilepsy Foundation believes children living with epilepsy should have access to the full range of school and school-related experiences in the least restrictive environment. Allowing trained, non-medical personnel to administer emergency seizure medication for a child with a seizure treatment plan would be a first step. We ask you stand with the epilepsy community of Connecticut and support RB 5303 to help children with epilepsy. We would be happy to discuss this issue with you. Please feel free to contact Linda Wallace at [lwallace.efct@sbcglobal.net](mailto:lwallace.efct@sbcglobal.net) or 860-346-1924 with any questions or follow-up.

Sincerely,



Linda Wallace  
Executive Director  
Epilepsy Foundation of Connecticut



Philip M. Gattone, M.Ed  
President & CEO  
Epilepsy Foundation

CC: State Senator Duff, Vice Chair  
State Representative Fawcett, Vice Chair  
State Senator Linares, Ranking Member  
State Representative Whit, Ranking Member  
State Representative Candelaria  
State Representative Hewett  
State Representative Hoydick  
State Representative Rose  
State Representative Vargas  
State Representative Wood