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March 3, 2014

Support for House Bill No. 5303 – AN ACT CONCERNING ACCESS TO EMERGENCY MEDICINE FOR CHILDREN WITH EPILEPSY

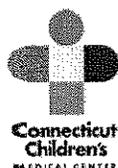
Dear Members of the Connecticut State Senate Committee on Children:

We, members of the professional advisory board of the Epilepsy Foundation of Connecticut, are writing to register our support to allow trained personnel in schools to administer emergency antiepileptic medications to school children in the case of an unexpected prolonged seizure. On behalf of the roughly 5000 children and adolescents in Connecticut living with Epilepsy, we welcome and support measures to assure that children with epilepsy have appropriate and timely access to safe and effective medication. Stopping seizures promptly allows children to more fully participate in their educational experiences.

The use of antiepileptic medications in schools has become a very important topic to many families of children with epilepsy. All child neurologists are aware of multiple situations in which children with epilepsy who are prescribed antiepileptic medications have incurred unnecessary medical risks because educators and child care service providers refuse to make the medications readily available onsite. Children have been excluded from programs because of the false belief that certain treatments must be administered or applied by a medical professional, or that extensive monitoring is required. In addition to the medical risks and potential injury, when calling 911 or other emergency responders instead of administering emergency antiepileptic medications on-site in a timely manner, families often incur significant expenses as well as unnecessary ambulance rides and emergency room visits.

This bill allows school personnel to implement the treatment plan given to them by the parents and the child's physician. The actual judgment and decision to give emergency antiepileptic medication is the same judgment and decision the parents would make at home: **any caregiver who would consider calling "911" should have already considered giving the prescribed emergency antiepileptic medication first.** Just as Boy Scout leaders are trained in first aid and by-stander CPR (cardio-pulmonary resuscitation) by the American Red Cross, trained school personnel should be in the position to implement the emergency antiepileptic medication treatment plan (which is much easier to learn than by-stander CPR). This bill allows school personnel to implement "first aid" and help a child in need. The benefits of giving these safe and effective medications as early as possible are enormous!

Federal and state laws guarantee every child/student the right to participate in free, appropriate public education in the least restrictive setting. Schools are also required to provide many health-related services, including administering medicine, if needed, to students with disabilities, as either a reasonable accommodation or a related service. The purpose of these laws is to ensure that children with chronic health conditions—like epilepsy—can be educated in the least restrictive environment and participate in extracurricular and recreational activities with their peers. Because antiepileptic medicines, including rectally or orally administered diazepam, can be administered by nonmedical personnel who have received proper instruction, lack of access to a doctor or full-time nurse is not an acceptable reason to



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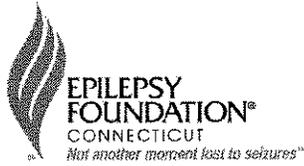
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refuse to administer the medication on-site or to deny a child or student access to certain school activities. The Epilepsy Foundation wholly supports these principles as being in the best interest of the child.

The Epilepsy Foundation of Connecticut urges providers of childcare and educational services to work with the child, his or her parents and the child's treating physician to learn how and when to administer the appropriate treatment. Schools and service providers should, along with the child's parents and as appropriate, the treating physician, develop a plan for ensuring that adequate measures are taken to administer the treatment and that the appropriate staff is properly trained to do so. Such a plan may legally be a part of an Individual Health Plan (IHP), an Individual Education Program (IEP), a Section 504 plan or simply a plan required to ensure compliance with the Americans with Disabilities Act of 1990 (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 need for administration of emergency antiepileptic medications.

The basis for an Individual Health Plan (IHP) is to benefit schools by:

- Protecting individual and district liability of school boards and administrators
- Documenting compliance with federal and state laws and regulations
- Providing data about individual needs for staffing, professional development, policies, and cost-effective use of school and community resources

The basis for an Individual Health Plan (IHP) is to benefit children and families by:

- Avoiding unnecessary risk, restriction, stigma, school absence, and additional illness
- Coordinating academic goals with physical, social, and medical needs
- Emphasizing academic and medical continuity
- Increasing sensitivity by both school staff and peers about the medical needs of others
- Providing medically timely and convenient access to medication at all times, and
- Outlining individualized crisis and emergency management needs

An IHP provides opportunities for collaborative planning and problem-solving between school staff and parents. Every student with a health impairment or physical disability needs documentation of their needs and the services to be provided through an IHP. The IHP clarifies the provision of medication, monitoring of health status, and other aspects of health management.

What are the consequences of not having an Individual Health Plan (IHP) that includes the use of emergency antiepileptic medications?

- Students can't reliably receive medication as needed
- School staff do not understand the precautions necessary to avoid hazardous situations
- School staff can't assist students to overcome obstacles to participation and achievement

Emergency antiepileptic medication can be safely used for management of acute repetitive seizures in both children and adults. Diazepam is approved by the FDA for the intermittent management of



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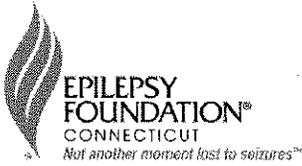
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break through seizures in patients with epilepsy on stable regimens of anti-epilepsy drugs. Midazolam is also commonly used and is approved for buccal administration in other countries. Midazolam intranasal preparation is in the process of seeking FDA approval for emergency use. Emergency anti-epileptic medication helps to control bouts of increased seizure activity. The Epilepsy Foundation of Connecticut is well aware of concerns raised in opposition to our view. We feel that these concerns regarding evaluation and assessment of the seizure (wrong dosing and dangers of the drug and its recommended administration) are unfounded. Studies in both children and adults with epilepsy show emergency anti-epileptic medications to be safe and effective in stopping breakthrough seizures. No significant medication-related adverse events are seen with repeated administration of this anti-epileptic medication.

Because anti-epileptic medicines can be administered by personnel who have received proper instruction, lack of access to a doctor or full-time nurse is not an acceptable reason to delay urgent administration of the medication on-site, or to deny a child or student access to certain school programs. The Epilepsy Foundation of Connecticut wholly supports these principles as being in the best interest of the child. Our position—that trained, school personnel can safely administer emergency anti-epileptic medications—is endorsed by the undersigned members of the Professional Advisory Board of the Epilepsy Foundation of Connecticut, a panel comprised of clinicians, scientists and other professionals with expertise and interest in seizure disorders.

Thank you for your consideration and support for this bill which will help protect children with epilepsy.

If you have any questions please feel free to contact Dr. Jennifer Madan Cohen jcohen01@connecticutchildrens.org, who will serve as the Professional Advisory board liaison for this matter.

Submitted respectfully to the Connecticut State Senate Committee on Children,
Signed Electronically by Members of the Professional Advisory Board of the Epilepsy Foundation of CT
(alphabetical):

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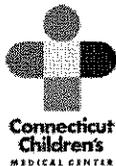
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