

March 14, 2012

The Honorable Terry B. Gerratana, Co-Chair
Public Health Committee
Room 3000 Legislative Office Building
Hartford, CT 06106

The Honorable Elizabeth B. Ritter, Co-Chair
Public Health Committee
Room 3000 Legislative Office Building
Hartford, CT 06106

RE: Support for SB 369 “AN ACT CONCERNING AUTHORIZATION FOR THE USE OF FEEDING TUBES AND ANTIEPILEPTIC MEDICATIONS IN SCHOOL SETTINGS.

Dear Senator Gerratana and Representative Ritter:

On behalf of children with epilepsy in the state of Connecticut, the National Epilepsy Foundation greatly appreciates the efforts of our supporters in the Legislature to codify CT law to ensure that children are protected and able to receive medications in school that they might need for their seizures in an emergency situation. We look forward to working with legislators to pass the best possible bill to expand the protection of our children’s best interests, their rights – and indeed, their lives. Children with epilepsy must be assured access to their medication easily and readily when needed. It could be a matter of life or death.

It is crucial that students have timely access to diastat, an FDA approved medication for administration by any parent or caregiver in the rare circumstances that a child may be having life-threatening cluster seizures. It has been suggested that such needed medications can only be given by medically trained personnel, when in fact Diastat®, or rectally administered diazepam, is a safe product to use with predetermined dosing, requiring no medical intervention, and its use can help prevent more serious and life-threatening events from occurring. Unfortunately, the Epilepsy Foundation is aware of multiple situations in which people with epilepsy who are prescribed Diastat® have been denied access to school or school-related activities, or have incurred unnecessary medical risks because educators and child care service providers call 911 rather than give the medications immediately. In addition to the risk to the child of delaying immediate treatment with a readily available medication which is prescribed for the child, families have incurred significant expenses, ambulance, emergency room, and doctor visits when 911 or other emergency responders are called instead of administering Diastat® on-site in a timely manner.

Because this medication can be administered by anyone who has been instructed in its proper use for the individual child, including parents, caregivers, or school personnel in accordance with the child’s treatment plan, 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.

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 Diastat®. 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 IHP, an IEP, or simply a plan required to ensure the schools’ compliance with the 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, usually very rare, for the administration of Diastat®.

The manufacturer of the product would be happy to provide copies of the considerable documentation that exists on the safety of Diastat® for use by instructed parents and caregivers. As studies make clear, and as medical experts in epilepsy can attest, the use of Diastat® by lay people can be done safely and effectively. The Epilepsy Foundation is most concerned that assertions that medically trained professionals must administer this medication will result in children not having access to the full range of school and related experiences in the least restrictive environment because the child has a type of seizure for which Diastat® may be needed in an emergency. That would be wrong!

Thank you for your consideration and support.

Sincerely,

A handwritten signature in black ink, appearing to read "Tony Coelho". The signature is fluid and cursive, with the first name "Tony" and the last name "Coelho" clearly distinguishable.

Tony Coelho, Interim CEO
Epilepsy Foundation

CC: Members of the Public Health Committee