

March 10, 2010

The Honorable Gloria Romero
Chair, Senate Education Committee
Room 2090
State Capitol
Sacramento, CA 95814

RE: Support for SB 1051 (Senator Huff) “**Emergency medical assistance: administration of Diastat®**”.

Dear Senator Romero:

On behalf of the more than 3 million Americans living with Epilepsy, the Epilepsy Foundation applauds and supports initiatives in California to assure children with epilepsy will have appropriate and timely access to life saving medication. I am writing to encourage your support of SB 1051 that would permit any trained, nonmedical personnel to administer FDA approved Diastat® and, in turn, ensure that children are not needlessly denied access to the full range of educational experiences.

It is a shame that this bill is even necessary in order for children in school to have access to a medication which is FDA approved 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 CA 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 refuse to make the medications readily available onsite. Children have unnecessarily been excluded from such programs because some administrators or health professionals have mistakenly asserted that these treatments must be administered or applied by a medical professional or that extensive monitoring of the child is required. In addition to the risk to the child of delaying immediate treatment with a readily available medication 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 joins the sponsors of SB 1051 in wholly supporting these principles as being in the best interest of the child. Our position that trained, non-medical personnel can safely administer Diastat® is endorsed by medical experts in the treatment of epilepsy in children, including our Professional Advisory Board comprised of clinicians, scientists and other professionals with expertise and interest in seizure disorders. Again, it bears repeating that the FDA itself has approved the use of this

medication as safe and effective to be administered by non-medical caregivers who have been instructed to use it.

For most people, conventional medications that can be taken orally are effective in controlling seizures. A number of children in particular though, are susceptible to prolonged, cluster, or status seizures; these seizures may last longer than five minutes in duration and can cause serious injury and even death. For these children, a doctor may prescribe Diastat® to be administered on an emergency basis. Following standard procedures, as prescribed by the treating physician, it is crucial that caretakers administer Diastat® in a timely fashion 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 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®.

It should be noted that access to Diastat® 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 medications like Diastat® should also be available in private schools.

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 non-medical personnel can be done safely and effectively. The Epilepsy Foundation is most concerned that assertions that medically trained 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 for SB 1051.

Sincerely,



Eric Hargis, President and CEO
Epilepsy Foundation

CC: Senate Education Committee
Senator Robert Huff - Vice Chair
Senator Elaine Alquist
Senator Loni Hancock
Senator Carol Liu
Senator Curren Price
Senator Joe Simitian
Senator Mark Wyland
Daniel Alvarez, Chief Consultant, Senate Education Committee