

  
**Jeanne A. Carpenter**  
**Epilepsy Legal Defense Fund**

## **Advocacy Activities regarding Access to Diastat AcuDial in Child Care Programs and Schools**

The following outlines selected initiatives undertaken by the Foundation's Jeanne A. Carpenter Epilepsy Legal Defense Fund to ensure full access to Diastat for children in school and day care. The mission of the Fund is to protect the civil rights of people with epilepsy by promoting education, advocacy and increased access to legal services. A primary strategy of the Fund is to manage a technical assistance and attorney referral service for persons with epilepsy experiencing discrimination. The Fund also provides legal support to attorneys that accept its referrals, to other attorneys nationwide handling epilepsy-related discrimination cases, and to the Foundation's affiliates.

### Child Care and Other Non-School Settings

As a result of our negotiations extending over one year, we have reached an agreement regarding Diastat administration with KinderCare Learning Corporation, which operates the KinderCare centers, the largest child care chain in the U.S. Effective late 2008, KinderCare adopted a written policy and protocol under which staff at its 2200 centers nationwide will administer Diastat and provide other epilepsy-related first aid based on the written instructions of the child's physician and parents. Previously, KinderCare centers would rely on 911 for needed care, placing the child's health at risk and imposing unnecessary costs on the family. The policy, which was reviewed by EF's PAB members, can serve as a national model.

We have been collaborating over the last two years with a law office in California on litigation against the second largest chain of child care centers in the U.S., Tutor Time Learning Centers, LLC (TT), which had refused to allow staff to administer Diastat to children in their care. We helped draft the lawsuit that was filed against TT in California federal court, alleging that TT's policy violates the Americans with Disabilities Act and state antidiscrimination law. We alleged that TT is required to have its staff administer Diastat to ensure equal access for children with epilepsy to child care, and that doing so does not create an unreasonable modification of TT's operations. The Foundation was successful in petitioning the court to become a co-plaintiff in the litigation, allowing us to bring claims on behalf of all children with epilepsy nationwide affected by TT's policy. The LDF participated in a mediation of the case in California in December 2008, in which general agreement on a settlement was reached. In March 2009, counsel for TT submitted a proposed settlement agreement for our review. We hope to reach a nationwide settlement quite soon.

A settlement was reached in a case (in which the Foundation was a co-plaintiff) against a New York day care provider (a franchisee of TT) which had refused to allow staff to administer Diastat. The terms of the settlement are confidential.

A large child care program run by the Army at Fort Campbell in Kentucky has refused to allow its staff to administer emergency medication to a three-year old boy, Kenneth Rutherford, whose father, Sergeant Rutherford, is stationed at the base. The situation is particularly troubling because Sergeant Rutherford was to be deployed to Afghanistan, leaving Mrs. Rutherford (who would be prevented from completing her college degree) with sole responsibility for Kenneth's care. After the Fund's efforts to resolve the situation through educational efforts with the base failed, the Fund referred the matter to a cooperating law office. This office filed a lawsuit against the Army, which alleged that its refusal to administer the medication violates Section 504 of the Rehabilitation Act, which prohibits disability-based discrimination by federal agencies. Settlement discussions have recently begun in the case. For a video of a very sympathetic TV report on the case, see <http://www.newschannel5.com/Global/story.asp?S=7452320>.

Based in part on oral and written guidance provided to several of LDF's cooperating law offices, informal agreements were reached with several smaller child care providers to administer Diastat.

We are advocating with the Kentucky Board of Nursing to ensure that unlicensed staff in group homes and other care facilities serving people with epilepsy are authorized to administer Diastat (thus avoiding unnecessary reliance on 911 for care). Recently, working with the local affiliate and a cooperating law office, we were able to convince the nursing board's general counsel to propose an amendment (we we drafted) to the board's rules permitting permit trained unlicensed care facility staff to administer Diastat. The proposal is going to the full board for a vote soon, and is likely to be adopted.

### Schools

In 2008, we published a comprehensive legal resource for parents and lawyers providing guidance on ensuring access to emergency antiseizure medication in schools and child care -- *Legal Rights of Children with Epilepsy in School & Child Care: An Advocate's Manual*. In several chapters, the manual provides detailed practical guidance on effective advocacy strategies in these areas as well as sample model policies and guidance on resolving disputes. We also published a brochure for families setting out similar guidance. Both publications may be downloaded from [www.epilepsyfoundation.org/epilepsylegal/genattyresources.cfm](http://www.epilepsyfoundation.org/epilepsylegal/genattyresources.cfm). Bound copies may also be ordered from the Foundation's Web site.

In order to raise awareness with parents on their children's legal rights in this area, the Director of the Fund authored an article on the rights of children with epilepsy to services in school and child care. The article, which appears in the July 2007 issue of *Exceptional Parent Magazine*, focuses in part of the right to access emergency antiseizure medication.

The LDF collaborated with the Foundation's local affiliates and a cooperating law office in drafting a bill assuring access to Diastat in Tennessee's schools. The bill, which was signed into law in 2008 by the Tennessee Governor, authorizes public and private schools to allow volunteer non-medically trained school staff to administer Diastat pursuant to a student's individual health plan, if a school nurse is not immediately available to administer the medication. Such volunteer personnel must be trained by a RN employed by the school based on guidelines to be developed by the State Departments of Education and Health. Previously, state law permitted only registered nurses to administer the medication.<sup>1</sup>

Two California schools which did not have nurses on-site refused to allow their teachers or other non-medically licensed staff to administer Diastat. The Fund referred the parents of the children to a law office in California, and assisted in drafting a legal opinion letter for the state department of education which concluded that the schools' policy violates the children's rights under the Individuals with Disabilities Education Act, which requires schools to provide medical assistance and other related services to ensure full access to educational services. The law office was able to negotiate favorable settlements in both cases. The LDF has helped promote several similar successful resolutions in other states regarding schools' restrictive Diastat policies.

We are working with the local affiliates to advocate for policy changes to ensure that unlicensed school staff are permitted to administer Diastat in California. Currently, many individual California school districts, based on their independent and overly restrictive reading of state law requirements (which lack clarity), permit only school nurses to administer the medication. Because school nurses are in very short supply, school districts frequently rely on 911 to provide care; the delay in treatment until 911 arrives can place children's health at unnecessary risk. In March 2009, a bill was introduced into the California State Legislature that would expressly require that Diastat and other prescription medications only be administered by nurses. Strategies to address the bill are being developed, such as seeking an amendment to allow administration of Diastat by volunteer school staff with appropriate training.

---

<sup>1</sup> In addition, the law provides as follows:

- A school district is prohibited from assigning a student with epilepsy or other seizure disorder to a school other than the school for which the student is zoned because the student has a seizure disorder
- Emergency medical services must be called whenever the medication is administered to provide necessary monitoring or transport to safeguard the health and condition of the student
- At least one school employee, if available, shall serve as a witness when a volunteer administers the medication
- Volunteers are afforded immunity from liability if acting reasonably and consistent with relevant state guidelines
- Parents/guardians are to provide the school with a written authorization for nurse or volunteer administration, along with the medication and written instructions on its administration from the child's physician

