



Jeanne A. Carpenter

Epilepsy Legal Defense Fund newsletter

Protecting the civil rights
of people with epilepsy
through education,
advocacy and increased
access to legal services.

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Foundation Calls for Police Seizure Response Training

Following yet another in a series of dangerous mishaps involving a police response to a person experiencing a seizure, the Epilepsy Foundation is once again calling for police, emergency medical personnel and other first responders to undergo training and implement protocols to ensure they properly respond in these kinds of situations. The most recent report involves Michigan resident Daniel Belounea, who was taking a daily walk in his neighborhood when he experienced a complex partial seizure, which left him in a state of semi-consciousness. He was apparently unjustifiably tasered, clubbed, arrested, jailed and committed to a psychiatric facility for violent offenders — all based on non-threatening behaviors caused by a seizure.

Complex partial seizures are associated with repetitive involuntary movements, sometimes for up to 30 minutes, with post-seizure disorientation. Belounea needs to walk daily as a form of rehabilitation to help restore functioning in his legs; this functioning was impaired following brain surgery to treat his seizures. A person passing by noticed Mr. Belounea acting erratically and called police to report his behavior. When officers arrived on the scene, they apparently assumed that his failure to respond to their questions and his erratic involuntary movements amounted to resistance, and failed to recognize the obvious signs of a seizure. Furthermore, they failed

to inspect the medical alert bracelet he was wearing, which indicates clearly that he has epilepsy.

According to police reports, when Mr. Belounea was unresponsive to police direction, the bag he was carrying was kicked by police from his hand, and when he flailed his arms involuntarily, he was tasered, sending 50,000 volts of electricity through his body; hit with a police baton; threatened at gunpoint; and handcuffed behind his back. (The handcuffing itself is dangerous for persons experiencing a seizure, as it can lead to further seizure-related agitation and struggling, possibly causing asphyxiation or even cardiac arrest.) He was then prosecuted for assaulting police officers and disorderly conduct, notwithstanding considerable evidence, including the state's own mental health evaluation, confirming that his actions were involuntary and solely the product of a seizure.

Then, apparently because of a gap in Michigan law, Mr. Belounea was forced to plead not guilty by reason of insanity, rather than being permitted to submit evidence that he lacked the mental and physical capacity to commit the crimes for which he was charged. Because State law requires that all persons who have been adjudicated not guilty by reason of insanity be committed for a 60-day

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The Legal Defense Fund (a program of the Epilepsy Foundation®) provides legal guidance to individuals experiencing epilepsy-related discrimination and their families, along with referrals to a nationwide network of cooperating law offices. The Fund was established in memory of Jeanne A. Carpenter, a lawyer, Epilepsy Foundation® Board member, and a person with epilepsy. She was a tireless advocate for people with epilepsy from the time she was first diagnosed with the condition until her untimely passing in 2003.



Connecting with the Fund

Over 200 law offices now participate in the Fund's referral network (agreeing to provide up to three hours of pro bono assistance), with about 300 open cases on which the Fund is providing assistance. The Fund provides legal guidance and lawyer referrals on a broad range of discrimination issues, such as the following:

- Employment discrimination
- Accommodations needed in school and day care programs
- Criminal justice matters (such as arrest for seizure-related behavior)
- Federal entitlement programs
- Driving restrictions
- Improper handling of seizures by first responders

Individuals experiencing discrimination related to epilepsy and their representatives are invited to request legal guidance or a referral to an attorney through the Fund's Web site, www.epilepsylegal.org, or by calling 1-800-332-1000, and selecting option 4 when prompted. Attorneys representing persons experiencing such discrimination may contact the Fund for assistance via email (Legalrights@efa.org) or by calling 1-301-459-3700.

Seizure Response Training • *continued from p. 1*
mental health evaluation (to determine if they present a threat to themselves or others), a man who posed no risk to anyone was forced to languish in a penal institution housing violent criminal offenders (where he experienced at least two subsequent seizures). He was discharged from the psychiatric facility after a stay of more than three weeks.

Fortunately, he was released from the psychiatric facility before the end of the two-month evaluation period (after advocacy by his treating physician, Dr. Marianna Spanaki-Varelas, M.D., PhD, the Foundation and its local affiliate) and is doing well at home. However, too many other people experiencing seizures have had encounters with police that have resulted in serious permanent injuries or even death.

Training and Advocacy Assistance

There must be reforms in the practices of police and other first responders to ensure appropriate training and protocols are put in place with respect to the recognition and management of persons experiencing seizures. Police departments and other first responder agencies are encouraged to contact the

Foundation affiliate serving their community to request that the agency provide training. To locate the affiliate serving a particular community, see www.epilepsyfoundation.org and go to "Your Community" at the top of our home page.

In 1992, the Epilepsy Foundation developed a training curriculum for police nationwide on appropriate seizure recognition and response, along with an accompanying video: "Take Another Look: Police Response to Seizures and Epilepsy." The materials were developed with the Police Executive Research Forum under a grant from the Department of Justice, as part of a larger educational project to promote compliance with the ADA. These materials were distributed to over 20,000 police departments nationwide. Key excerpts from the curriculum are posted on the Foundation's Web site. Recently, the Department of Justice has posted a shortened version of the video on its Web site. This is part of the Department's initiative to help state and local law enforcement agencies understand their responsibilities under the Americans with Disabilities Act. This Justice Department video is available online at <http://www.ada.gov/videogallery.htm>.

The Foundation is in the process of developing an updated training curriculum for police and other first responders on seizure recognition and management.

The Fund is tracking and supporting cases involving challenges to dangerous first responder practices and would like to offer assistance to other attorneys, as well as to individuals with epilepsy and their families.

Here is an example of client statements about the Fund:

"I wanted to tell you how appreciative I am for the follow through you have provided to me. I will indeed speak to this law firm and will keep you posted on my findings. I am also grateful for the ability to speak with someone who will provide an initial several hour consultation at no additional cost to me. Thank goodness for your legal defense fund."

DOT Review of Rules on Truck Drivers with Epilepsy — Exemptions Now Considered

The U.S. Department of Transportation's Federal Motor Carrier Safety Administration (FMCSA) has established a Medical Review Board (MRB), which is examining the qualification standards for interstate truck drivers with epilepsy and other medical conditions. This standard provides that people with a diagnosis of epilepsy or who use anti-seizure medication are prohibited from driving trucks in interstate commerce. This standard, as published in federal regulations (see title 49 Code of Federal Regulations, section 391.41(b) (8)), disqualifies people with epilepsy regardless of their present ability to control seizures. These regulations only cover drivers of trucks with a gross weight of more than 10,000 pounds who cross state lines as part of their job, and those who transport products within a state that originated in another state.

The regulations, which have been on the books for more than 20 years and are based on outdated medical information, establish an unfair blanket exclusion policy, as they do not allow for an individualized review of the actual safety risks posed by particular drivers. To date, legal challenges to the federal regulations have been unsuccessful. However, as noted below, the FMCSA will now consider requests to be exempted from these driving restrictions.

The MRB is composed of five distinguished practicing physicians; Dr. Mathew Rizzo (a professor of neurology at the University of Iowa Medical College) will be leading the review of the neurological standards, which include the requirements pertaining to epilepsy. The MRB will provide recommendations to FMCSA on the development of science-based physical qualification standards. DOT will then issue a proposed rule to revise its current standards — unfortunately, from start to completion, the rulemaking process may be quite time-consuming, taking two years or more. More up-to-date information about the work of the MRB can be found on its Web site, at <http://www.mrb.fmcsa.dot.gov>.

The MRB held its initial organization meeting in August 2006, and staff of the Foundation testified about the urgent need to bring the standards up to date to conform to current medical knowledge about epilepsy and driving. It is expected that the MRB will convene a panel of experts to begin review of the epilepsy standards in early 2007, at which time there will be public meetings of the MRB to address the standards. The Foundation will be working closely with the MRB to help ensure that DOT adopts an appropriate set of qualification standards, which are based on an individualized assessment of each driver's qualifications.

The FMCSA has recently announced that it will, for the first time, consider requests to be exempted from its rule prohibiting driving by persons with a history of epilepsy. On October 13, 2006, the agency published in the Federal Register a notice about four exemption applications it had received and is now considering. Based on the notice, the Agency apparently will grant a two-year exemption (which may be renewed) from the driving prohibition if it finds that granting such an exemption will not compromise safety of the roadways.

According to senior staff at the FMCSA, a waiver request must be sent in writing to John H. Hill, Administrator, Federal Motor Carrier Safety Administration, U.S. Department of Transportation, 400 Seventh Street, SW., Washington, DC 20590. The applicant should submit, along with the request, a letter by a physician regarding the applicant's medical fitness to drive. The information may be provided by a general practitioner and/or an epilepsy specialist. In addition, the letter should provide documentation attesting to the applicant's safe driving record. Agency staff indicate that there currently are no formal criteria applicable to this review process. Requests will be reviewed by physicians who contract with the FMCSA and the MRB, and reviews may be expected to take 180 days to complete.

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A Few (or More) Good Attorneys Wanted

The Fund is seeking to expand its growing network of cooperating attorneys (both those with or without experience in disability law are welcome). Each network participant is asked to commit to providing each client referred with free services to a maximum of three hours (including an initial consultation), and to consider, as appropriate, continuing representation on a pro bono, sliding fee scale or contingency fee basis (many referrals will involve only short-term assistance

such as providing oral advice or making a call to resolve a dispute). In return, the Fund's staff offers technical assistance and variety of resources (see below). The Fund maintains a database on the practice areas of cooperating attorneys and the type of case referrals desired, and always limits referrals based on this information.

Individual attorneys and law offices may register on-line directly from the Fund's Web site to start receiving case referrals. Simply go to www.epilepsylegal.org, click on "Attorney Registration," and provide the requested information. Soon after a registration is completed, the Fund sends out a welcome package, with resources and background information.

Foundation Board Chair Provides Congressional Testimony Urging ADA Amendments: Congress Introduces Bill

On September 13, 2006, Epilepsy Foundation Board Chair Tony Coelho, testifying at an oversight hearing on the ADA held by the House of Representatives Committee on the Judiciary, Subcommittee on the Constitution, provided his personal perspective on why amendments to the Act are required to restore it to Congress' original intent. As a result of several Supreme Court decisions, the ADA's coverage has been drastically cut back. Most significantly, persons with so-called "correctable conditions" (that is, controlled with medication or other "mitigating" measures) such as epilepsy, diabetes and multiple sclerosis are generally no longer protected from discrimination. The courts have found that most times these people are considered "too functional" to be regarded as having a disability (see article in last edition of this newsletter on the topic). "The federal courts, relying upon the Supreme Court's failure to carry out Congressional intent, misapplication and misunderstanding of the ADA in employment have so narrowly construed the ADA as to have effectively written people like me out of our own bill," stated Mr. Coelho, who has epilepsy and is a former Member of Congress and original author of the ADA. "It's time to restore the promise of the ADA that Congress intended." Mr. Coelho, along with Professor Robert Bergdorf, another hearing witness, recommended specific statutory amendments to address this concern. For more information on this hearing, see <http://www.epilepsyfoundation.org/epilepsyusa/ada20061004.cfm>.

Following the hearing, on September 29, 2006, a bill was introduced in Congress to address these concerns. The bill, H.R. 6258, the "Americans with Disabilities Act (ADA) Restoration Act of 2006," was introduced by House Judiciary Committee Chairman F. James Sensenbrenner, Jr. (R-WI), House Minority Whip Steny H. Hoyer (D-MD), and Ranking Member of the Judiciary Committee John Conyers (D-MI). The Bill would amend the ADA to cover individuals with a physical or mental impairment as defined in the bill (or a record of an impairment or a perceived impairment), and to specify that the determination whether one has a covered impairment shall be made without regard to the individual's use of mitigating measures or whether the impairment is episodic.

Selected Recent Cases

- *A.H. v. ADESA San Antonio, Inc.* (S.D. Tx. Settled 2006). The plaintiff, A. H., who experiences severe memory limitations as a result of medication and surgery to treat his epilepsy, was discharged from a position as a car maintenance worker for a large auto auctioneer, allegedly after forgetting to complete a work assignment. This lawsuit also alleged that the employer failed to provide A.H. a reasonable accommodation in the form of reminders about work assignments and schedules and simplified instructions on job duties, and repeatedly harassed him (calling him stupid and sometimes purposely providing false work schedules). After A.H. filed a complaint with the EEOC, the Agency found an ADA violation and the employer declined to enter into settlement negotiations. The Fund provided extensive technical assistance to A.H.'s attorney, and committed to filing an amicus brief in support of A.H. The case was settled successfully (and the Fund's willingness to participate in the

litigation apparently was a contributing factor); the terms of the settlement are confidential.

- *Morris v. Oldham County Sheriff's Department* (pending Ky. State Court). Mr. Morris, a deputy sheriff, was terminated after reporting that he experienced a seizure (off the job), and filed litigation in Kentucky State Court under the ADA and the State employment discrimination statute. The Sheriff's Department claimed that his condition rendered him incapable of performing critical law enforcement duties in a safe manner; however, medical evidence does not support this and Mr. Morris claims that the Sheriff's Department failed to offer adequate accommodations. The Fund devoted considerable resources in helping to prepare the lawsuit and in drafting a brief opposing the Department's motion to dismiss the case. Fortunately, in June 2006, the court denied the Department's motion to dismiss the case. The judge also ordered the parties to attempt mediation, and a trial date will be set if a settlement cannot be reached.

In her order overruling the defendant's motion, the judge found that the plaintiff's epilepsy is a disability covered under the ADA, even though associated physical impairments can be mitigated by medication. Unfortunately, the majority of cases decided in recent years have ruled otherwise, finding that if seizures are well-controlled by medication (and there are no significant medication side effects or other associated impairments), one's epilepsy is not covered by the ADA. (See Article on ADA Restoration Bill, which would address this concern.)

- *Grant v. Alamo Community College District* (W.D. Tex., settled 2006). Plaintiff, Ms. Grant, who has a seizure disorder, was discharged from her position as a child care worker at a college day care center. She was discharged despite the fact that her doctor cleared her to return to work

(after experiencing a couple of seizures) with some minimal restrictions that would not interfere with essential job duties. The employer failed to respond to Ms. Grant's request to consider reassigning her to another position as a possible accommodation. The Fund referred Ms. Grant's attorney to an expert to assist in determining how to ensure appropriate accommodations for Ms. Grant. The attorney was able to settle the case; the settlement terms are confidential.

- *Simpson v. Raytheon Co.* (E.D. Tex., settled 2006). Ms. Simpson was employed as an engineer by Raytheon for several years before being diagnosed with a form of epilepsy in which her seizures are triggered by chemical exposure. Although informed of this sensitivity, Raytheon refused to grant Ms. Simpson's request to disclose information on the extent of her chemical exposure in the workplace, so as to allow her to take precautions. The Fund referred the individual to Advocacy Inc., the designated protection and advocacy agency for Texas, which filed a lawsuit alleging violations of the ADA and state law. In August 2006, Ms. Simpson and her counsel entered into mediation and reached a settlement with her former employer. The terms of the settlement are favorable but are confidential.
- *Estate of Becerra v. City of Nashville* (Tn. Fed. Ct. filed 2005). Nashville EMTs, paramedics and firefighters, responding to a man experiencing a complex partial seizure (Mr. Becerra), allegedly forced the man onto his stomach, and restrained him, tying his hands and ankles behind his back. Mr. Becerra died shortly after being restrained in this manner, potentially the result of asphyxiation or cardiac arrest. The action, which is pending, raises civil rights claims and seeks monetary damages. The City of Nashville filed a motion to dismiss, claiming that the EMTs involved are immune from liability.

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Unfortunately, the majority of cases decided in recent years have ruled that if seizures are well-controlled by medication (and there are no significant medication side effects or other associated impairments), one's epilepsy is not covered by the ADA.

Recent Cases • *continued from p. 5*

Specifically, the City claims it should not be liable because the EMTs involved were not properly trained in the use of restraint and therefore did not act intentionally (a showing which is necessary to establish liability in these circumstances). The court denied this motion and the defendants have appealed that decision to the 6th Circuit Court of Appeals, where the case is still pending.

Cooperating Attorney Profile

The Fund greatly appreciates the strong advocacy of Julie Carter on behalf of folks with epilepsy experiencing discrimination. Ms. Carter is a nationally recognized expert on disability law. Since 2004, she has practiced with a Missouri firm in the areas of disability discrimination, nursing home abuse and neglect, and medical malpractice. Prior to that, she practiced employment discrimination law for five years and also served as the legal director of the Arizona Center for Disability Law. In 2003, she was selected as a recipient of the Joseph P. Kennedy Foundation Fellowship in Public Policy, serving as disability advisor to United States Senator Tom Harkin from Iowa, a lead sponsor of the ADA and major Senate voice in protecting the rights of people with disabilities.

Ms. Carter was one of the very first attorneys to join the Fund's attorney network and has been extremely dedicated in providing high quality legal services. Examples of Ms. Carter's work on cases referred by the Fund include the following: An individual was terminated from her nursing-related administrative position, apparently based on the employer's concerns that she may have difficulty communicating with callers, as a result of a speech impairment which was a side effect of medication for her epilepsy. In July 2006, Ms. Carter filed a federal lawsuit in Kansas district court on the individual's behalf, alleging unlawful termination and retaliation. In other recent cases, Ms. Carter assisted an individual to represent herself at an administrative hearing addressing whether her insurance company should pay for certain testing related to her seizures, represented a hotel waiter fired after experiencing a seizure, and is advising a college student with epilepsy denied accommodations necessary to remain in his dorm room.

Resources for Attorneys, Affiliates and Consumers

WEB SITE

We have recently enhanced the Attorney Resources Section of our Web site, at <http://epilepsyfoundation.org/epilepsylegal/attyresources.cfm>. For example, see the newly added materials in our brief bank at <http://epilepsyfoundation.org/epilepsylegal/attyresources/briefbank.cfm>. Also, there are a number of consumer resources that may be helpful, available at <http://epilepsyfoundation.org/epilepsylegal/legalinfoctr.cfm>.

ON-LINE DISCUSSION FORUM

We have begun an on-line discussion forum open only to cooperating attorneys. The forum may be accessed directly through our Web site (see "Attorney Resources"). This forum is intended to encourage sharing of information on case developments involving epilepsy-related discrimination and to provide a vehicle for soliciting tips on best practices and advocacy strategies. Please feel free to respond to currently posted queries or to add new ones. Users of the forum can receive automatic email notices when a new message has been posted in an area of interest (simply click on the "subscribe to this message" or click on the "Help" button to learn about this and other features of the forum).

CASE LISTS, DOCKETS AND BRIEFS

The Fund is continually updating our case lists around critical issues areas, which we are glad to make available. These lists summarize court decisions on, for instance, coverage of epilepsy as a disability under the ADA and access to medical care in prison for persons with epilepsy. We also maintain dockets which track cases currently being handled by cooperating attorneys and others in two of our priority issue areas: employment discrimination matters, and personal injury claims involving first responder handling of seizures (including improper restraint use). We can make available these dockets and some complaints and briefs in these cases (in addition to those found on our Web site).

ATTORNEY NETWORKING

We have expanded our network of cooperating attorneys to approximately 200 nationwide. We would be glad to identify attorneys in your state or elsewhere with whom you may consult on cases and share resources.

Advocacy for Access to Emergency Medication in Schools

Many public school systems around the country have taken the position that only registered nurses may administer emergency medication for seizures. Because in most schools nurses are not available throughout the school day and/or for extracurricular activities, this policy may effectively deny many students with epilepsy their right to equal educational opportunity and place their health at risk.

The standard out-of-hospital medication for treatment of prolonged or cluster seizures is Diastat[®] Acudial,™ a rectally administered preparation of diazepam. (Diazepam is in a class of drugs called benzodiazepines, which are central nervous system depressants.) The medication is FDA-approved and was specifically developed to be administered by people without medical training, such as parents, teachers and other caregivers. Virtually all studies conclude that Diastat is a completely safe and effective treatment, even when administered by caregivers without specialized medical knowledge. Other medications, which also may be administered by non-medical personnel, may be sometimes appropriate.

Because the medication is particularly effective when administered within 15-30 minutes of seizure onset, and permanent neurologic damage may result with a delay in administration, non-licensed school staff must be immediately available. Nevertheless, many schools which do not have nurses on on-site rely on emergency medical services (911) to respond to a student experiencing a seizure. This practice, in addition to delaying treatment, can result in unnecessary psychological trauma to the child and his or her parents, and, of course, saddle the family with potentially significant hospital bills.

In fairness, it should be noted that school administrators are frequently concerned about whether state nurse practice acts — which establish standards on licensing and educational requirements for nursing care — prohibit administration of the medication by school employees other than licensed nurses. However, in a case in which the Fund had significant involvement, an Ohio court recently found that non-medically trained school employees such as teachers' aides are indeed authorized under state law to

administer the medication (Lancaster School District Support Association v. Board of Education, Lancaster City School District, Ohio Ct. of Common Pleas

Seizures Requiring Emergency Medication

Most seizures last less than one to two minutes and are harmless. However, some people may experience prolonged seizures (of a few minutes or more) or severe repetitive (or "cluster") seizures. Emergency medication is needed to address these conditions, as they may lead to a serious medical emergency, called "status epilepticus." SE is defined as a seizure lasting 30 minutes or longer (though some experts use 10 minutes as a benchmark), or as intermittent seizures lasting that period from which the patient does not regain consciousness. There are an estimated 100,000-150,000 cases of this condition per year, with the largest proportion of cases among children under the age of ten. The condition can cause permanent neurological damage. For more information on epilepsy medications, including Diastat,[®] see the Foundation's Web site at <http://www.epilepsyfoundation.org/answerplace/Medical>.

March 6, 2006). The reasoning of the court should have broad application to other states.

The court found that administering Diastat does not require "specialized knowledge, judgment and skill derived from the nursing sciences," and therefore is not covered by the Ohio Nurse Practice Act. Also, the court noted that administering Diastat to a child experiencing a generalized seizure constitutes a medical emergency, and therefore falls under an exception to the Act. In this case, there apparently were a number of safeguards in place which the court found clarified that the school district may (under a separate provision of Ohio law) direct non-licensed school personnel to administer the medication. These safeguards included a signed parental request, instructions from the prescribing physician and appropriate training for employees.

The school employees' union which had originally challenged the school board's policy has appealed

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Advocates' Corner • *continued from p. 7*

this decision. The Epilepsy Foundation and its Central Ohio affiliate recently filed a friend of the court brief in support of the school district. The brief, along with the lower court decision, are available online at <http://epilepsyfoundation.org/epilepsylegal/genattysources.cfm>.

The Fund also is working with the Foundation's affiliates in other states to assure full medication access. For instance, in California there are ongoing discussions regarding the State Department of Education policy which prohibits school personnel other than nurses from administering Diastat.

The Department's position is that the State Nurse Practice Act and Education Code limit this authority to only licensed nurses. The position of the Fund and affiliates is that these statutes do in fact permit such staff to administer the medications, provided certain safeguards are in place, such as adequate training.

All advocates and family member who are currently confronted with a denial of full access to emergency seizure medication in school, day care, aftercare or other settings are asked to contact the Fund. The Fund is attempting to track these cases nationwide and support legal action to address this serious issue.

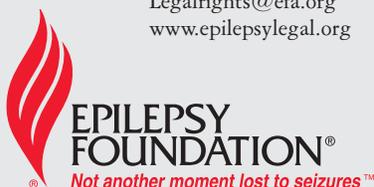
DONATING TO THE FUND

Won't you consider making a contribution to help support the Jeanne A. Carpenter Epilepsy Legal Defense Fund? Your donation will expand our capacity to provide legal assistance to the many people around the country who experience epilepsy-related discrimination every day. To make a tax deductible contribution, simply go to www.epilepsylegal.org/donate.cfm or click on "make a gift," which appears at the top of the Defense Fund's Web site (www.epilepsylegal.org).



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