



Jeanne A. Carpenter

Epilepsy Legal Defense Fund newsletter

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

Epilepsy Foundation Joins Lawsuit Seeking to Ensure Child Care Centers Provide Emergency Epilepsy Medication

On February 29, after receiving court approval, the Epilepsy Foundation joined as a plaintiff in a lawsuit against a national chain of child care centers that refuses to administer a potentially life-saving medication to children with epilepsy. The suit was originally filed in California federal district court on behalf of an eight-year-old boy, Cade Rager, when a child care center in Mira Loma, California operated by the chain, Tutor Time Learning Centers, LLC, refused to provide him the medication. The boy's physician prescribed the medication to be administered rectally by his parents or other caregivers in the event he experiences a prolonged seizure, which can cause brain injury or death if not promptly treated.

The Foundation, as an "organizational" plaintiff in this action, is representing the interests of the many other children with epilepsy around the country who may have been prevented from attending any of the 200 child care centers affiliated with the Tutor Time chain due to its discriminatory policy against the administration of this medication.

The medication, diazepam rectal gel (sold under the brand name Diastat AcuDial), is the standard out-of-hospital FDA-approved medication for prolonged seizures. It was specifically approved by the FDA for adminis-

tration by people without medical training — such as parents, child care workers and school personnel — who can do so safely and easily. Children with epilepsy are particularly susceptible to prolonged seizures that may cause serious brain injury or death if not promptly treated, yet the child care provider's only plan was to call 911, which would result in a dangerous delay in treatment.

Many child care providers quickly understand that administering this medication is the right and necessary action to take. Unfortunately, many other providers do not understand and may put children at risk and create an unnecessary burden on families who cannot find safe child care. Because this medication can be easily administered by non-medical personnel who have received proper instruction, lack of access to a doctor or full-time nurse is not an acceptable reason for a child care provider's refusal.

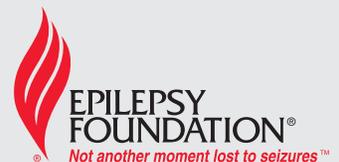
The Rager family and the Foundation are being represented by the San Diego office of Protection and Advocacy, Inc. (PAI), the designated "protection and advocacy" agency for California (which is federally mandated to provide legal services on behalf of persons with disabilities). PAI claims in its lawsuit

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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.



Emergency Medication • *continued from p. 1* (which the Legal Defense Fund helped prepare) that, under the Americans with Disabilities Act, which prohibits discrimination against persons with disabilities in child care centers and other public accommodations, Tutor Time has an obligation to modify its policy against administering this medication. This policy

change is necessary to afford Cade and many other children with epilepsy an equal opportunity to participate in the program.

A similar lawsuit, against an Army-operated child care center that refuses to administer this medication, is currently pending in Kentucky (for more information on that case, see the article below).

The Fund Helps File and Resolve Major Discrimination Cases

The Fund provided a number of resources to help with the case... [which] assisted plaintiffs' counsel in demonstrating appropriate police protocol in responding to seizures.

The following outlines some cases in which the Fund has provided support to its cooperating attorneys — helping persons with epilepsy fight discrimination. For more information about these and other cases handled by the Fund's cooperating attorneys, and for copies of briefs and other litigation documents, contact the Fund at legalrights@efa.org.

First Responder Wrongful Death Cases Settlements

Villanueva v. Township of Bloomfield. This case — in which it was alleged that Bloomfield New Jersey police restrained a man experiencing a seizure, causing his death — recently settled for \$2 million, one of the largest settlements ever for a case of this kind. The lawsuit alleged as follows: Santiago Villanueva, 35, was experiencing a seizure on April 16, 2002 at a garment factor where he worked. Officers (who were trained as EMTs), arriving on the scene in response to a 911 call, deemed Mr. Villanueva combative. The police restrained Mr. Villanueva by placing pressure on his back and neck, despite insistence by his co-workers that such force was unnecessary. Mr. Villanueva stopped breathing at one point during the incident, but started again before reaching the hospital, where he died. The medical examiner determined the cause of death to be homicide by mechanical asphyxiation. According to one of the attorneys representing Mr. Villanueva's family, the defendants' attorneys argued that the police used reasonable force to restrain Mr. Villanueva based upon their perception that he was violent and presented a threat. However,

the evidence showed that at the time of the incident, Mr. Villanueva was in a post-seizure state of confusion and did not present a danger.

The Fund provided a number of resources to help with the case, including the Foundation's curriculum guide for trainers of law enforcement personnel on how to recognize and appropriately respond to persons who are experiencing seizures (*Take Another Look: Police Response to Seizures and Epilepsy*). This assisted plaintiffs' counsel in demonstrating appropriate police protocol in responding to seizures. The Foundation is in the process of updating these training materials.

Gates v. Broomfield County. A settlement was also reached in this case, which also involved the death of a man experiencing a complex partial seizure after he was restrained by paramedics and police officers. On September 3, 2005, the responders, located in a community outside of Denver, were called to the home of Michael David Gates, age 42, by his wife, who witnessed him having a complex partial seizure. As alleged in the complaint, the responders attempted to prevent Mr. Gates from leaving his bedroom, forcing him onto his bed face down. At least one responder applied pressure with a knee to Mr. Gates' back to restrain him and they handcuffed him behind the back at the same time. The responders transported Mr. Gates to the ER, at which time he was unconscious. He was placed on life support for 36 hours. The treating doctor indicated that Mr. Gates was suffocated. A favorable monetary settlement was reached (the amount is confidential).

Access to Emergency Anti-Seizure Medication in School and Child Care

Matters of J.M. and L.H. Two California schools which did not have nurses on-site refused to allow their teachers or other non-medically licensed staff to administer emergency medication (diazepam rectal gel) to children who experienced prolonged seizures. 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. For instance, in the case of J.M., the school district agreed to assign a licensed vocational nurse at the child's neighborhood school to be available to administer the medication. The agreement was incorporated into J.M.'s individualized education plan and school health plan. The school district originally proposed to transfer J.M. to another school far from his home with a full-time nurse, but this option was rejected.

Rutherford v. U.S. Army. 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. Because efforts to find alternative safe child care have been unsuccessful, Mrs. Rutherford has been unable to complete her college degree. The situation is particularly troubling because Sergeant Rutherford soon will be deployed to Afghanistan, leaving Mrs. Rutherford 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 the Kentucky Protection and Advocacy System. After months of failed efforts to resolve the case, the agency filed a lawsuit against the Army, alleging its refusal

to administer the medication violates Section 504 of the Rehabilitation Act, which prohibits disability-based discrimination by federal agencies. More information about the case,

How the Fund Can Help

Consumers: 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. The Fund's staff will provide prompt legal guidance and determine whether a referral to a lawyer is necessary for direct legal advice or representation. The lawyers to whom the Fund refers cases have agreed to provide an initial consultation and services to a maximum of three hours at no cost (sometimes additional services are available at no charge or a reduced hourly rate). Once a referral is made, the lawyer will evaluate a potential case and advise on the next steps.

Attorneys: Those representing persons experiencing epilepsy-related discrimination may contact the Fund for assistance via email (legalrights@efa.org) or by calling 301-459-3700. The Fund can provide a variety of resources such as: legal research, briefs, case lists, expert referrals, and medical information. In cases of national significance, we can consider filing an amicus brief and/or providing a grant to help defray litigation costs. For more information, see <http://epilepsyfoundation.org/epilepsylegal/attresources.cfm>.

Accepting Case Referrals: Individual attorneys and law offices that wish to assist the Fund by accepting case referrals may register with the Fund on-line directly from the Fund's Web site. Simply go to www.epilepsylegal.org, click on "Register as an Attorney," and provide the requested information. Soon after a registration is completed, the Fund sends out a welcome package, with resources and background information.

including a link to television coverage, is available at the Fund's Web site, www.epilepsylegal.org (see "What's New").

Employment Discrimination

Russo v. SYSCO Food Services, 488 F.Supp.2d 228 (N.D. N.Y. 2007). In this case, in the which the Fund provided significant legal assistance, the court ruled in favor of a trucking company employee with epilepsy who was denied reassignment to non-driving jobs as an accommodation. SYSCO's refusal was based a company doctor's finding that Mr. Russo could not operate commercial vehicles or equipment (relevant to these jobs) unless he was seizure-free for two years. The court

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Discrimination Cases • *continued from p. 3*
ruled that Mr. Russo was regarded as substantially limited in his ability to work, and was therefore covered under the ADA's provisions protecting persons who are regarded as disabled. Just before trial on the issue of Mr. Russo's qualifications for the positions sought, a settlement was reached. The employer agreed to pay back pay and to make a contribution to Mr. Russo's pension plan covering

terminated Mr. Whitehead based on its apparent nationwide policy of denying such positions to persons who cannot qualify, under U.S. Department of Transportation rules, for a medical certificate to drive trucks interstate. The rules disqualify persons with epilepsy or who take antiseizure medication such as Mr. Whitehead. UPS claims that the ability to drive trucks across state lines is an essential function of the position, asserting that truck mechanics are required to perform this task when picking up broken down trucks or test driving repaired trucks. However, the evidence indicates that Mr. Whitehead's position and others like it do not involve any interstate driving. Mr. Whitehead, who has not experienced a seizure in over 15 years, is extremely well-qualified for this position, having worked successfully for many years in a similar position. In response to a complaint filed by Mr. Whitehead, the Equal Employment Opportunity Commission (EEOC) issued a finding of discrimination in this case, concluding that UPS' policy violates the ADA, as it screens out persons with disabilities and is not job related or consistent with business necessity. The Fund provided a grant to Mr. Whitehead's counsel to help defray litigation expenses, and is providing ongoing legal assistance.

Cerminara v. City of Pittsburgh. A 27-year veteran Pittsburgh Fire Department captain was allegedly suspended from his position after being diagnosed with epilepsy despite the fact that his treating neurologist cleared him to return to work after placing him on antiseizure medication. The City suspended Mr. Cerminara based on its policy requiring that firefighters with epilepsy must be off antiseizure medications and seizure-free for one year before returning to work. The Foundation believes that this off-medication policy is not medically justified and actually encourages risk taking that is directly contrary to promoting public safety. One of the Fund's participating attorneys filed suit under the ADA, claiming that the City's policy discriminates against firefighters with epilepsy without fairly evaluating their ability to safely perform their duties.

an additional five years. This allowed Mr. Russo to retire — his goal — and to receive a pension of about 50% more than he would have received without the employer's contribution. Attorney fees also were included in the settlement.

Whitehead v. UPS. In February, a suit was filed, under the ADA and New York State Human Rights Law, against United Parcel Service on behalf of Mr. Jay Whitehead, who was denied a truck mechanic job with the company. UPS

New Resources

New Brochures: The Fund has recently developed a new pamphlet, "Education and Day Care: Advocating for Your Child." The pamphlet provides an overview of federal laws that mandate access to services in school and day care programs for kids with epilepsy, and outlines practical advocacy strategies for families. The pamphlet is available on the Fund's Web site at <http://epilepsyfoundation.org/epilepsylegal/LegalFactSheets.cfm> (see Education heading). Copies may be ordered from the Epilepsy Foundation (at a small charge) by calling 866-330-2718 (ask for item 199EDC). Also, The Foundation's pamphlet "Legal Rights, Legal Issues" has been updated and is also available at the above Web site and through phone order (item 076 Law, ask for 2007 version). This document discusses a variety of legal issues, including employment, driver licensing, education, insurance and the availability of federal disability benefits.

Education Advocacy Manual: The Fund is in the process of developing a manual, for attorneys and families, addressing the rights of children with epilepsy to access educational and child care services. The manual will cover such subjects as accommodations in school and child care and special education services and the duty to administer emergency antiseizure medication; it provides model approaches and advocacy strategies in these areas. Portions of the manual are posted on the Fund's Web site at <http://epilepsyfoundation.org/epilepsylegal/genattyresources.cfm>. Check back for updates.

Disclosing Information about Epilepsy in the Workplace

People with epilepsy are often confronted with the issue of whether they are required to disclose information about their health condition to their employers. Prior to the passage of the ADA in 1990, employers often used disability-related inquiries or medical examinations to exclude or otherwise discriminate against individuals with disabilities — particularly “invisible” disabilities such as epilepsy — without determining if the individual was capable of doing the job. In passing the ADA, Congress was careful to address this concern by including provisions restricting this practice. These provisions reflect Congress’ intent to both protect the rights of workers to be judged on merit alone, while also protecting the rights of employers to make reasonable inquiries about workers’ qualifications. Below is some guidance on these issues, along with some suggestions on when an employee with epilepsy may wish to voluntarily disclose his condition. Some of the information below is based on guidance issued by the Equal Employment Opportunity Commission (EEOC), which enforces the employment provisions of the ADA (see www.eeoc.gov/facts/epilepsy.html and www.eeoc.gov/policy/docs/guidance-inquiries.html).

Job Seekers. Job applicants with epilepsy should know that medical inquiries are permissible only after a conditional offer of employment has been made. Prior to a job offer, an employer may not inquire about whether one has a disability or about its severity; neither may it make any inquiry that is likely to elicit information about a disability. Accordingly, an employer may not ask an applicant questions relating to, for instance, whether he has epilepsy or seizures, uses any prescription drugs, or has missed work in the past because of a health condition. Applicants are not required to disclose their health condition during the job application process, unless there is a need for an accommodation in that process. If an applicant voluntarily discloses that he has epilepsy, the employer can only ask if an accommodation is needed and if so, what type. Learning that an applicant has epilepsy is not a sufficient reason for a potential employer to withdraw a job offer if the individual can perform the essential duties of the job, with or without reasonable accommodations (see below for information on reasonable accommodation).

After an Offer has been Made. At this point, an employer may require that the individual respond to a medical inquiry or undergo a medical examination, as long as all applicants in that job class or category are required to undergo such an exam or inquiry. An employer may ask the applicant questions about his epilepsy, such as relating to the use of medication, the type and frequency of seizures, and the need for assistance if he has a seizure at work. The employer also could send the applicant for a follow-up medical examination or ask him to submit documentation from his doctor answering questions specifically designed to assess the applicant’s ability to perform the job’s functions and to do so safely.

After Employment Begins. A person may experience a seizure in the workplace or an employer may begin to notice that the person’s medical condition might be affecting his ability to perform the job or do it safely. In these instances, an employer may make a medical inquiry or ask the employee to submit to a medical examination. But such inquiry or examination must be job-related and consistent with business necessity. This means there must be a valid reason to believe that an employee’s ability to perform the job is impaired by epilepsy (or some other medical condition), or that the condition poses a significant risk of substantial harm to himself or others. In addition, an employer may ask an employee with epilepsy to justify the use of sick leave by providing a doctor’s note or other explanation, as long as it requires all employees to do so. If an employer requires an employee to go to a health care professional of the employer’s choice, the employer must pay all costs associated with the visit(s).

Safety Concerns. Prior to denying a job opportunity to an employee or applicant whom the employer believes poses a threat to health or safety, the employer must conduct an individualized assessment of the person’s ability to safely do the essential functions of the job. The assessment must be based on “reasonable medical judgment that relies on the most current medical knowledge and/or the best objective evidence.” To meet this burden, in the case of an applicant or employee

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Advocates' Corner • *continued from p. 5*

with epilepsy, the individual should be examined by a neurologist, preferably one with expertise in epilepsy. Any medical examination must be limited to determining whether the individual can perform his job without posing a significant threat to health or safety, with or without reasonable accommodation. Accordingly, in most situations, an employer cannot request an employee's complete medical records, because they are likely to contain information unrelated to whether the employee can perform the essential functions of the position without posing such a direct risk.

Voluntary Disclosure Related to Reasonable Accommodation. Where an employee with epilepsy requests an accommodation, he may be required to substantiate that his condition is a disability covered under the ADA or the state's antidiscrimination law, and that he needs a reasonable accommodation. (Note, however, that based on decisions of the Supreme Court, persons with so-called "correctable" conditions, that is, those controlled with medication or other "mitigating" measures, may not be protected from employment discrimination under the ADA. This may include persons with epilepsy whose seizures are controlled with medication. However, many state antidiscrimination laws provide significantly greater protections than the ADA for persons with epilepsy and other conditions that can be "corrected.") Job accommodations include alterations in duties, the work environment, or the way job functions are performed that enable a qualified individual with a disability to perform the essential functions of the position. For a discussion of possible accommodations for persons with epilepsy, see the Job Accommodation Network publication at www.jan.wvu.edu/media/epilepsy.html.

The documentation to be provided, such as a letter from the physician, should describe the individual's seizures and their severity and frequency, along with any side effects of antiseizure medication; indicate the extent to which the epilepsy limits the employee's ability to perform the job duties; and justify why the requested reasonable accommodation is needed. The employer may require the employee go to an appropriate health care professional of the employer's choice if the employee provides insufficient documentation from his treating physician (or other health care professional).

In this case, the employer should explain why the documentation is insufficient and allow the employee an opportunity to provide the missing information in a timely manner. The employer also should consider consulting with the employee's doctor (with the employee's consent) before requiring the employee to go to a health care professional of its choice.

The EEOC's guidance on epilepsy in the workplace (www.eeoc.gov/facts/epilepsy.html) notes that:

Although many individuals who have seizures do not require any first aid or assistance, an employee who might need assistance may want to work with his employer to create a plan of action that includes such information as: who to contact in an emergency; warning signs of a possible seizure; how and when to provide assistance; when to call an ambulance, etc. The employee and employer also should discuss who in the workplace should know this information. Some individuals also might want to ask their employers for an opportunity to educate their co-workers about epilepsy to dispel any misperceptions or unsubstantiated fears they may have about the condition.

Of course, an important consideration in deciding to disclose relates to whether the employer is legally obligated to provide the desired accommodation. If there are questions on this issue, the Fund can provide guidance or make a referral to an attorney who can provide legal help.

If epilepsy is not affecting job performance or relationships in the workplace, it is generally inadvisable to disclose the condition — because discrimination, unfortunately, remains a real possibility. The decision to disclose is a personal one that should be based on a weighing of the potential costs and benefits, including:

- Need for accommodation to perform the job
- Need for accommodation to avoid discipline or termination
- Need for accommodation to protect health and safety
- Whether modification may be obtained without disclosing disability
- Risk of stigma and harassment
- Risk of loss of privacy
- Potential for more successful and supportive employment experience

DOT Medical Expert Panel Recommends Relaxing Truck Driver Rules

A U.S. Department of Transportation panel of medical experts recently recommended that the Department significantly relax its current rules governing the medical certification of interstate truck drivers with epilepsy. The current DOT rules prohibit driving of commercial motor vehicles (those weighing more than 10,000 pounds) across state lines by anyone with a diagnosis of epilepsy or who uses anti-seizure medication. However, guidance issued for the current rules states that truck drivers with a history of epilepsy may be certified to drive if they have been off antiseizure medication and have been seizure-free for 10 years or more. (It appears that this guidance is discretionary and that DOT medical examiners, who issue the medical certifications for interstate drivers, generally disqualify drivers with epilepsy, relying on the DOT rule rather than the guidance.)

A medical expert panel (MEP) established by the DOT to advise its Medical Review Board (MRB) found that these standards are inappropriate and overly restrictive. (The MRB was set up in 2006 to review all DOT medical standards for interstate truck drivers, and is charged with making recommendations to DOT for revisions to its regulations on this subject.) The MEP, during a January 28, 2008 meeting, recommended that DOT adopt a standard that provides as follows: Interstate truck drivers with epilepsy may be certified if they are seizure-free for eight years on or off antiseizure medication; if they are off medication, they must be seizure-free for eight years since medication cessation, or if on medication, the individual must have been on a stable medication regime for at least two years. This represents a major improvement over the current guidance for the rule and is much more medically justifiable.

The MEP reached its conclusion after first determining the acceptable level of seizure risk for commercial motor vehicle drivers. The MEP noted that several organizations, including the

UK Department of Motor Vehicles, have adopted an annual seizure risk of two percent as an acceptable threshold, and thus, the MEP adopted that level as the appropriate standard. (The two percent upper limit ensures that the annual risk for experiencing a seizure while driving will be less than 0.5% percent, assuming a 50-hour work week.) The MEP determined (relying on data from one particular study) that the two-percent annual seizure risk level is reached after one is seizure-free for eight years; consequently, it selected eight years as the appropriate period of seizure freedom.

However, the MRB disagreed with the MEP's recommendation, and concluded that it would be more appropriate for DOT to follow the guidance contained in its current rules — allowing driving by persons with a history of epilepsy only if they have been off antiseizure medication and have been seizure-free for 10 years or more. This decision was reached without substantive discussion of the MEP's findings. But one member of the MRB objected, noting that this standard is overly restrictive and will likely discourage some individuals from disclosing information about seizures.

According to DOT staff, the Agency will consider the input provided by both the MRB and the MEP in determining its next course of action. One option may be to issue a proposed revision to its regulations. Alternatively, the Agency may seek additional input at subsequent meetings of the MRB.

DOT maintains a Web site summarizing activities related to its review of the truck driving rules — go to www.mrb.fmcsa.dot.gov. Also see the fall 2006 issue of this newsletter (available at www.epilepsylegal.org) for background information on the DOT rules; that issue of the newsletter also provides information on how one can apply for an exemption from the rules, and obtain certification to drive despite a history of epilepsy. DOT has yet to rule on any of the dozen or more exemption requests submitted to date.

The current DOT rules prohibit driving of commercial motor vehicles (those weighing more than 10,000 pounds) across state lines by anyone with a diagnosis of epilepsy or who uses anti-seizure medication.

Cooperating Attorney Profile

The Fund is very appreciative of the advocacy efforts on behalf of people with epilepsy by Mindy Farber, a cooperating attorney with the Fund. Mindy is a nationally respected employment and labor law attorney and Board Member for the National Center for Labor and Employment Law. She has practiced law for over 28 years and has extensive experience working with both management and employees. In her early career, Ms. Farber served as an attorney in the Civil Rights Division of the U.S. Department of Labor, as Vice President of the Baltimore Women's Law Center, and as a Partner in the Bethesda Maryland law firm of Paley, Rothman, Goldstein, Rosenberg, & Cooper. Ms. Farber currently manages a successful law practice, Farber Legal, LLC, in Rockville, MD (see www.farberlegal.com), where she represents clients in all matters relating to employment and labor law. She also represents clients in related areas of constitutional law, business law and civil litigation.

Ms. Farber was one of the first attorneys to join the Fund's network and has very actively advised individuals referred by the Fund. One example of Ms. Farber's work on an epilepsy-related case was her representation of an individual who was employed with a federal agency as a manager. This individual, who experienced uncontrolled seizures, requested a job reassignment to an administrative position as a reasonable accommodation. The agency denied the accommodation request twice despite having received detailed medical documentation from the individual's treating neurologist and primary care physician, both of whom recommended the reassignment. Ms. Farber assisted this individual with filing a complaint. The matter eventually settled, with the individual receiving an accommodation and continuing employment with the agency. In another case, based on Ms. Farber's advocacy, a child care worker with epilepsy, who was removed from a position based on unsubstantiated fears about safety, was returned to that position and is working successfully.

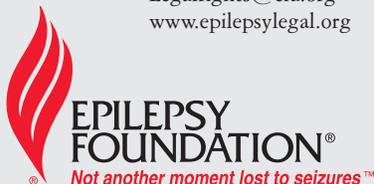
DONATING TO THE FUND

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 donation," which appears at the top of the Defense Fund's Web site (www.epilepsylegal.org).



EDITOR Gary Gross
Jeanne A. Carpenter Epilepsy
Legal Defense Fund

PUBLISHER Epilepsy Foundation
8301 Professional Place
Landover, MD 20785
301-459-3700
Legalrights@efa.org
www.epilepsylegal.org



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