



Jeanne A. Carpenter

Epilepsy Legal Defense Fund newsletter

Issue No. 8 • Fall 2011

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

Epilepsy Foundation Supports Access to Medication for California Students

In recent years, the Epilepsy Foundation has received a number of reports from consumers whose children are prescribed Diastat (a rectally administered diazepam) or other FDA approved treatments and are denied access to schools, daycare, school-related activities, or have incurred unnecessary medical risks, because schools and child care service providers refuse to make the medications readily available onsite. Because these medicines, including Diastat, are designed and FDA approved to be safely administered by lay people, family and caregivers who have been educated in its delivery, lack of access to a doctor or 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. In addition, federal and state law is clear that students who need medical or related services while participating in school and school activities are entitled to receive those services. Therefore, the Foundation joins families, medical experts, and advocates in demanding that children and students who use medications in school receive them promptly when needed.

A case of interest to the epilepsy community, and any school child who needs medications, is *American Nurses Association (ANA) v. Jack O'Connell*. In this case, the ANA challenged a settlement agreement between the American Diabetes Association

(ADA) and the California Superintendent of Education. The agreement allowed unlicensed school personnel to be trained to monitor administration of insulin for students with diabetes when a school nurse was not available. There is currently a severe shortage of school nurses in California; there are only about 2,800 school nurses to care for the over six million students in California public schools, creating a ratio of about only one school nurse for every 2,200 students. In fact, only about five percent of California public schools have a full-time school nurse, 69 percent have a part-time school nurse, and about 26 percent have no school nurse at all. Without the agreement to allow trained staff to administer insulin to students when a school nurse is not present, some students would likely not receive insulin doses that are medically necessary. This reality notwithstanding, the ANA filed this challenge to the agreement and the plans of the state education system to make the medication available, arguing that the California Nursing Practice Act (NPA) prohibits the administration of insulin without the presence of a nurse.

In 2008, the Sacramento County Superior Trial Court declared that the agreement regarding unlicensed school personnel

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The Epilepsy Legal Defense Fund (a program of the Epilepsy Foundation®) provides legal guidance to individuals experiencing epilepsy-related discrimination and their families, along with referrals and legal support to a nationwide network of cooperating law offices. The Fund was established in memory of Jeanne A. Carpenter, an attorney, 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.



Access to Medication • *continued from p. 1*
provision was invalid. Although expressly acknowledging that the outcome adversely affected not only the educational opportunities of students with diabetes, but also their health and safety, the trial court concluded that the NPA prohibited unlicensed persons from administering medication categorically and that the California Education Code did not authorize unlicensed school personnel to administer insulin to students with diabetes.

hibits non-medical school personnel from administering insulin to students with diabetes. Moreover, the appellate court ruled that the NPA prohibits anyone but a nurse from administering any type of medication in any setting (outside of a few narrow exceptions), and that the federal disability laws do not preempt California's NPA, even in situations where there is no nurse present to administer insulin to a student.

In both the trial and appellate courts, the ADA and the California Department of Education argued that the NPA does not prohibit non-medical school personnel from administering insulin, that state law actually authorizes this practice, and that federal civil rights laws protecting students with disabilities preempt any such prohibition in state law, at least when a school nurse or other licensed person is not available to administer the medication.

The Epilepsy Foundation submitted an *amicus curiae* letter to the California Supreme Court urging that court's review on appeal to settle an important question of law. All of California's school children who require administration of medications at school could be adversely affected by this ruling, including children who require antiseizure medications such as Diastat.

The California Supreme Court is currently considering the case. It should be noted that many organizations have filed friend of the court briefs opposing the lower court's ruling, including the U. S. Department of Education (DOE) and the U.S. Department of Justice (DOJ). In a joint brief, the United States noted that it took no position on whether the Court of Appeals correctly interpreted California law in the case; however, it asserted that the Court of Appeal's interpretation of the California NPA, as applied to the case, conflicts with federal law to provide a free and appropriate education to students. Therefore, it is preempted by federal law. To review a copy of the brief filed by the DOE and DOJ, please see our website: www.epilepsyfoundation.org/resources/epilepsy/attyresources.

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.

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 provides 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.

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 welcome materials with resources and background information.

Furthermore, the trial court found that federal law (Section 504 of the Rehabilitation Act of 1973, Title II of the Americans with Disabilities Act, and the Individuals with Disabilities Education Act) did not preempt the NPA's prohibition against unlicensed school personnel administering insulin.

On appeal in 2010, the Third Appellate District applied an extremely broad interpretation of the California NPA, and affirmed the trial court's ruling that the NPA pro-

Are For-Profit Colleges Good Alternatives to Other Post-Secondary Education Options?

Congressional Hearings Held and Education Department Final Rule Issued on the "Gainful Employment" Rule

Many individuals with disabilities attend for-profit colleges and other career-training programs. This appears to be in part due to difficulties students with disabilities can face in the traditional post-secondary education environment, such as high grade and test score requirements, long waiting lists, and lack of adequate disability services. However, it appears there is data showing potential risks for people attending for-profit colleges.

For-profit colleges have been sharply criticized over the past year for their recruiting practices, which aggressively target low-income, minority, single parent, and disabled students. While these schools make enormous profits, many fail to provide adequate supports for their students, leaving students with massive debt, and no jobs to pay it off. Students enrolled in for-profit schools represent just 10 percent of all undergraduate students, but account for 44 percent of all student loan defaults.

For-profit colleges can provide a valuable educational opportunity for students, but these schools have also been reported to use aggressive recruiting tactics, focused heavily on vulnerable disabled students. Often, for-profit colleges make promises they do not keep, such as disability support services, employment advisors, and individualized attention. Even when a school does not fulfill the promises recruitment officers may have made, students

are still responsible for costs even if they decide to withdraw from the program.

A broad-based investigation of for-profit schools was launched by Senator Tom Harkin as a result of the rapid increases in the amount of federal financial aid and other federal student assistance programs flowing to these schools. The purpose of the investigation was to understand how well for-profit schools, many of which are highly profitable publicly traded corporations, are serving students and taxpayers. As part of this effort, Senator Harkin led five hearings and collected data from 30 for-profit schools. To review reports from the investigation led by Senator Harkin, see <http://harkin.senate.gov/help/forprofitcolleges.cfm>.

On June 2, 2011 the Department of Education released a final rule designed to hold for-profit colleges and career training programs accountable for preparing their students for employment. The regulation, known as the "Gainful Employment" rule ensures that schools which fail to demonstrate the effectiveness of programs to prepare their students for "gainful employment" would risk losing their eligibility to participate in federal education grant and loan programs. The rule mandates that programs would lose their eligibility to dispense federal student aid if, over the next four years, their graduates fail to meet new benchmarks for loan repayment and ratio of debt to income.

National Office Launches New Website

After much anticipation, the national Epilepsy Foundation launched its new and improved website on August 1, 2011. The site has a new look, streamlined navigation, enhanced technologies, and an enhanced e-communities design to support our growing online health community of 15,000. The site links to new Facebook pages and Twitter feeds, as well as a redesigned online store.

One of the most exciting features is our planned

new tool, WebEase. This is an online epilepsy self-management program designed to help those with epilepsy better manage their stress, sleep and medication adherence.

With new research content, features, and tools, the site will empower the Foundation to lead the fight to stop seizures, find a cure, and overcome the challenges created by epilepsy.

Please visit our site at www.epilepsyfoundation.org.

Fund Recognizes Contributions of Attorney Marc Shipon

Marc Shipon, of Pennsylvania, has been practicing disability law since 1992. He developed a special interest in epilepsy because he has seen how epilepsy has affected the life of his mother-in-law. Helping people obtain benefits has been a way in which Shipon has positively impacted the lives of people with epilepsy.

Shipon graduated from Villanova Law School in 1991, where he worked as an Intern in the law school's Community Legal Services Program. It was through this experience that Shipon first learned about social security disability practice. He saw how he could really help people who are no longer able to work or who have children with severe impairments. He opened his law practice in 1993 and has been working in the field of social security and personal injury matters ever since. Shipon is the Founder and President of USDISABILITY.COM, a division of the Law Offices of Ruch & Shipon. His firm specializes in handling social security disability claims and appeals nationwide as well

as personal injury and wrongful death claims. For more information about his firm, see www.usdisability.com.

Shipon has represented individuals referred by the Fund. One case involved a client who had been physically beaten, developed seizures, and became homeless for a while. Shipon was able to obtain benefits for her; she is no longer homeless and receives a decent income. In another matter, a person contacted the Fund seeking assistance on behalf of her sister, who had been denied social security benefits. Shipon guided this family through the long appeal process. He was eventually successful at obtaining benefits for the client.

In addition to maintaining a successful law practice, Shipon is a sustaining member of the National Organization of Social Security Claimants Representatives and a supporter of the Epilepsy Foundation, the Multiple Sclerosis Society, and the AIDS Law Project. The Epilepsy Foundation appreciates Shipon's commitment to helping people with epilepsy.

The Legal Defense Fund Helps File and Resolve Major Discrimination Cases

The following are some cases and advocacy initiatives in which the Fund has provided support to attorneys assisting 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.

Employment

Brown v. White River Township Fire Protection District. Brown, a Fire Prevention Chief, experienced a seizure on duty in 2008 but was not diagnosed with epilepsy until May 2009. After

being examined, he was cleared to return to duty by his personal doctor and the company's doctor. However, he was placed on administrative leave for disciplinary reasons (allegedly for conduct related to his disability). Brown requested reasonable accommodations; however the request was denied without explanation. After his official diagnosis of epilepsy in May 2009, he was again cleared to return to work, but his employer failed to reinstate him. A Defense Fund network attorney filed suit on Brown's behalf in federal court alleging that the employer failed to engage in the interactive process as required by the ADA.

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JACELDF

Brandt v. University of Colorado Hospital. Brandt was denied a position as a surgical technician with the hospital after disclosing her medical history of seizures. Although her condition is well controlled, the offer of employment was rescinded because of her history of seizures. A Legal Defense Fund network attorney filed a charge of disability discrimination with the EEOC and a civil suit asserting violations of Section 504 of the Rehabilitation Act. The cases are pending.

Lopez v. Pacific Maritime Association. The Fund joined an amicus brief with other disability rights organizations to address the blanket exclusion rule upheld by the 9th Circuit. In this case, at issue is the defendant's hiring policy to permanently exclude any applicant for employment as a longshoreman if he screened positive for drugs or alcohol at any time during an application process. Lopez screened positive in 1997 and reapplied after he was clean and sober in 2004. He was excluded because of this one-strike policy. A copy of the brief can be reviewed on www.epilepsylegal.org/resources/epilepsy/attyresources.

In re: C.G. C.G. was employed with a tire and auto shop. His position required him to drive cars in the bay area of the shop for service. C.G. was placed on unpaid administrative leave after he experienced a seizure and was restricted from driving for six months in accordance with state law. Although C.G. made proposed accommodations, the employer failed to engage in the interactive process to determine a reasonable accommodation as prescribed under the ADA. The Fund provided resources to C.G.'s attorney to assist with the filing of the EEOC charge. The matter was settled at mediation.

Arrest for Seizure Related Behavior

In re: T.C. The Fund provided legal resources to the attorney of T.C., who experienced a seizure at home and emergency medical services (EMS) were called. Upon arrival of EMS, T.C. was wandering in his yard in a postictal state. Police officers allegedly immediately shot him with a taser and beat him with a club. Criminal charges, which were originally filed against him, were later dropped; however, T.C. pursued a civil claim for police misconduct. The matter was settled prior to litigation.

In re: P.A. P.A. was being treated by paramedics for a seizure. While in a postictal state, he ran from his house and commandeered the ambulance. He was charged

criminally. The Fund provided resources to P.A.'s attorney who was able to get the charges dismissed.

Access to Medication in Childcare

Rutherford v. U.S. Army. In 2008, a large child care program run by the Army at Fort Campbell in Kentucky refused to allow its staff to administer emergency antiepileptic medication to a three-year old boy, whose father was an officer stationed at the base. 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, which filed a lawsuit against the Army alleging that its refusal to administer the medication violates Section 504 of the Rehabilitation Act, which prohibits disability-based discrimination by federal agencies. The case was settled. The terms of the settlement are confidential.

Prisoner's Rights/ Medication

Galindo v. Reeves County, et. al. In November 2007, Galindo was sentenced to a 30 month prison term. Galindo disclosed his epileptic condition to prison officials and it was documented by medical staff during his intake. After his arrival, his medication was switched from Topamax to Dilantin, which is a less expensive antiseizure medication. During the period of his incarceration, Galindo missed several dosages of medication despite the pleas from his family and other advocates. The complaint states that Galindo's records indicate the prison failed to provide approximately 90 doses of his medication. It further indicates that Galindo was punitively isolated by prison officials for complaining about the deficient medical care. He experienced a fatal seizure in isolation and died. To review a copy of the civil complaint, see www.epilepsy-foundation.org/resources/epilepsy/attyresources.

Other Cases of Interest

R.K., et al. v. Board. of Edu. of Scott County Kentucky. R.K., a student with diabetes who requires administration of insulin during the school day, alleged that the school board violated R.K.'s federally protected rights by transferring him away from his neighborhood school and requiring him to attend a school with a full-time nurse on staff. The school district rejected R.K.'s request that a volunteer employee at his neighborhood school be trained to help him with his insulin administration. The U.S. District Court for the Eastern District of Kentucky granted the school board's motion for summary judgment on all of

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Epilepsy and Social Security Disability

By Marc Shipon, Esq.
Contributing Author

The federal government offers financial assistance and health insurance to people with epilepsy who qualify. The two primary financial assistance programs are Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). These programs are administered by the Social Security Administration (SSA). Epilepsy, if severe enough, can cause many symptoms which can impact a person's ability to work. If a person has epilepsy and the resulting symptoms are so severe that they are unable to hold a full time job, he or she may be eligible for these benefits.

Evaluating Your Eligibility

Generally, there are a few ways a person can be eligible for some type of Social Security disability benefit. The most common are:

- (1) If he/she worked enough and paid into Social Security (approximately 5 out of the last 10 years). People normally receive a yearly earnings notice from Social Security which would let you know if you are eligible;
- (2) If he/she did not work enough, he/she may still be eligible for Supplemental Security Income (SSI) if the household income is very low and there are limited assets of under \$3000 married or \$2000 single;
- (3) If he/she did not have enough credits and had too much income, the other possible way to be eligible is under widows benefits. You must be at least 50 years old and have been married at least 10 years.

The Application Process

If you are eligible, you must then apply. A person can apply for benefits by going to www.ssa.gov or by calling the Social Security Administration at 1-800-772-1213. On the forms, an applicant should list every physical and mental impairment, even if the impairment is not related to epilepsy. For example, a person may have other conditions in addition to epilepsy, such as diabetes, a learning disability, or a back impairment. If an individual has medical con-

ditions other than epilepsy, it is important that the conditions are well-documented and tested by a physician. An applicant can only include health conditions that are medically documented.

Once the application is submitted, it may take a few months at the initial level for the Social Security representative to make a decision. **The process can take a few months or years depending on the claim.** Medical evidence is necessary; therefore, an applicant should be sure that all evidence is submitted to support the application. It is important that you continue to receive medical treatment because SSA will rely on the results of medical tests to determine whether you can be found disabled.

If benefits are denied, an applicant must submit an appeal within 60 days after the denial or you will have to reapply for benefits. Once an appeal is filed, depending on the state, the case may proceed to the reconsideration level or it may proceed immediately to the administrative law judge level. The administrative law judge level is the first level where a claimant actually attends a hearing. Generally, this is the stage where most people obtain an attorney for assistance. The hearings usually take about 30 to 60 minutes. The judge asks the claimant a variety of questions about his/her disabilities, past work, symptoms, reasons why he/she is unable to work now, daily activities, etc. A claimant has to be careful how he/she answers the judge because one wrong answer can ruin the claim.

Generally, a person loses if the judge believes he/she is able to sustain a full time job based on all of the evidence and testimony. Therefore, attorneys or other advocates must be sure that all medical records are submitted and try to get reports from the client's doctors explaining why he/she is unable to sustain any type of full time employment. There are specific forms that doctors can obtain on different conditions. The law changes as a person ages, therefore it is easier to obtain benefits as a person gets older.

How to Improve a Client's Chances of Winning an Epilepsy Disability Case

Generally, a judge will evaluate the case based on the kind of seizures, the duration, frequency, and the residual effects. There are certain requirements your client has to meet to win. The following is the criteria required under the Social Security administration laws:

Social Security Disability listing 11.02 states:

Epilepsy – convulsive epilepsy, (grand mal or psychomotor), documented by detailed description of a typical seizure pattern, including all associated phenomena; occurring more frequently than once a month, in spite of at least 3 months of prescribed treatment. With:

A. Daytime episodes (loss of consciousness and convulsive seizures) or

B. Nocturnal episodes manifesting residuals which interfere significantly with activity during the day.

Social Security Disability listing 11.03 states:

Epilepsy – nonconvulsive epilepsy (petit mal, psychomotor, or focal), documented by detailed description of a typical seizure pattern including all associated phenomena, occurring more frequently than once weekly in spite of at least 3 months of prescribed treatment. With:

An alteration of awareness or loss of consciousness and transient postictal manifestations of unconventional behavior or significant interference with activity during the day.

Below are factors that a judge will consider when determining an epilepsy claim:

- **Does the claimant have ongoing relationship with a licensed physician?** Make sure the client goes to the doctor frequently and tells the doctor all his/her symptoms and frequency of seizures.
- **There must be a satisfactory description by the treating physician of the treatment regimen and response.** Make sure the client reports all of his/her symptoms and seizure activity, including a description of the seizures, side effects of medications, and any mental issues. The client should keep a seizure diary, and provide a copy to the doctor during each visit or bring it to the hearing for further documentation. If the client is a bad historian and not capable of recalling or describing all of his/her symptoms, it is helpful

for a family member or friend to accompany him/her to doctor's appointments and the hearing to make sure that everything happening to the client is described properly.

- **In every instance, the record of anticonvulsant blood levels is required before a claim can be allowed.** Make sure the client takes the antiseizure medications properly and gets his/her blood levels checked frequently in order to prove that the medications are being taken as prescribed. Even if the client has frequent seizures, the judge may deny benefits because the client fails to take his/her medication properly. Judges are looking for breakthrough seizures of "at least more than once a month" in spite of at least three months of prescribed treatment. The judge may also evaluate the medication side effects. Any side effects should be documented in the medical records.
- If the client experiences depression or a fear of leaving the home because of the seizures, **he should receive mental health treatment.** People with epilepsy may experience co-morbidities that impact their daily functioning. For example, if the client experiences behavior or mood problems such as depression, anxiety disorders, Attention Deficit Disorder (ADD), or chronic sleep problems, he should receive additional treatment from a psychiatrist or psychologist.
- Even if the client does not exactly meet the 11.02 listing, the case can still be won by convincing the judge that he/she is unemployable from full-time employment. Again, it is imperative that EVERY physical and mental condition the client has is well documented and included in the application for benefits. For example, if the client has a learning disability, try to obtain the school records and IQ tests. If the client has a back impairment, obtain orthopedic evaluations, an MRI, etc. Bottom line: Don't just focus on the epilepsy.
- Follow up with the client. Make sure the client goes to the doctor and includes all information in the medical records.

Edited for length by the Epilepsy Legal Defense Fund.

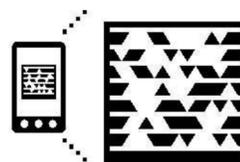
Discrimination Cases • *continued from p. 5*
 R.K.'s claims. In an amicus brief filed on June 7, 2011, the U.S. Department of Justice (DOJ) argued that the district court failed to apply the correct legal standards in analyzing whether the school district complied with Section 504 of the Rehabilitation Act's free appropriate public education (FAPE) and general non-discrimination requirements. In particular, the DOJ asserted that the school district was required to make an individualized, pre-placement evaluation of R.K.'s specific needs, and was not permitted to base the placement decision on a blanket policy or administrative convenience. The case, which is on appeal,

is pending. To review a copy of the civil complaint, see www.epilepsyfoundation.org/resources/epilepsy/attyresources.

Nobrenberg, et al. v. Linn County, et al. Two inmates from Linn County Jail filed suit against the facility for switching their mental health medications despite observations and recommendations by doctors. Both inmates suffered deterioration of their health conditions and were unable to aid in the defense of their criminal cases. A lawsuit was filed on behalf of the inmates by Disability Rights Oregon. The case was settled. To review a copy of the civil complaint, see www.epilepsyfoundation.org/resources/epilepsy/attyresources.

DONATING TO THE FUND

Please 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, go to <http://tinyurl.com/3dolpyc> or scan this tag with your Smartphone and instantly go to the Epilepsy Legal Defense Fund donation page to make your charitable donation now.

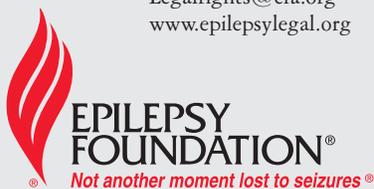


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