The Legal Defense Fund recognizes John T. Wagener for his advocacy on behalf of people with epilepsy.

Mr. Wagener is a trial attorney with 25 years of experience defending major product liability, catastrophic personal injury, insurance, and business litigation. As a partner with the Chicago law firm of Dressler & Peters, LLC, Mr. Wagener litigates cases throughout the country involving retail, manufacturing, distribution, and transportation sectors. His litigation experiences have allowed him to be involved in several cases of first impression, which have resulted in the creation of new legal doctrines by appellate courts in Illinois and other jurisdictions.

Mr. Wagener became involved with the Epilepsy Foundation approximately eight years ago after his youngest daughter was diagnosed with epilepsy. When his daughter was 15 years old, she collapsed in the park while having lunch with her friends. Under the care of Dr. Michael Chez, a pediatric neurologist, her seizure activity was brought under control with anti-seizure medications. Her condition remains controlled under the care of Dr. Michael Smith of the Rush Epilepsy Center in Chicago and Dr. Scott Metrick.

A few years ago, her insurer declined coverage of her medication for the regular co-pay when a generic version became available, pushing her monthly medication cost to over $1,200. Mr. Wagener sought the help of the Epilepsy Foundation. With the assistance of the Foundation, Mr. Wagener was able to get the issue resolved through the appeals process. “Although I handle insurance coverage work as part of my practice, the unique aspects of prescription drug benefit appeals was new territory to me”, says Mr. Wagener. “Because EFA helped our family, it is only fitting that I return the favor and help others in this niche area.”

Mr. Wagener has indeed returned the favor by helping clients referred by the Legal Defense Fund. He has assisted individuals and families with insurance appeals. For example, Mr. Wagener assisted a man who had maintained seizure control for seven years while prescribed Keppra. After his employer changed its health insurance carrier, the insurance
carrier made a decision to switch the client's medication from Keppra to a generic form of the medication. He was forced to pay over $800 for Keppra until he could no longer afford to do so. As a result of being switched to the generic medication, the client had a severe seizure and was hospitalized. With Mr. Wagener's advocacy, the insurance company agreed to provide full coverage of Keppra and the client was only required to pay the regular co-pay.

In another matter, Mr. Wagener assisted a client whose employer-based insurer would not agree to provide full coverage for his brand anti-seizure medication. The decision was based on language cited in the employer's contract with the insurer (which indicated that the employee was responsible for payment of the difference for the medication). Mr. Wagener prepared letters to the insurer on behalf of this client. As a result, the matter was reconsidered by the insurer, who agreed to provide full coverage of the medication and to reinstate the client's original co-pay. This client applauded Mr. Wagener for his efforts.

"Mr. Wagener is a champion in pursuing proper treatment, respect and dignity for those of us with epilepsy. . . ." said this satisfied client.

Mr. Wagener expressed that he is especially proud of his daughter's accomplishments despite her diagnosis of epilepsy. "She has not let epilepsy define her," according to Mr. Wagener. He shared that she competed for the U.S. Youth Soccer U-18 national championship with her club soccer team as a high school senior. She went on to play collegiate soccer and successfully graduated with a degree in Athletic Training.

Mr. Wagener resides in Green Oaks, IL with his wife, Mary Beth (a Medical Technologist), and two of their three children. In addition to being an accomplished attorney, he enjoys hiking with his Giant Schnauzers, attending car rallies with the Chicago MINI Cooper Club, cooking, and participating in local government. Mr. Wagener advocates for his local community, Village of Green Oaks, IL, by serving as Trustee -- an elected position he has held for over 15 years. He also serves his community as Regional Representative with the Solid Waste Agency of Lake County, IL, a position he has held for 10 years.

"Attorneys do pro-bono work for a variety of reasons. It is rewarding, at least for me, to be able to help those in need obtain the benefits that are properly due to them. Sometimes, all it takes is a little extra voice on their behalf to get things done", says Mr. Wagener. The Epilepsy Foundation and the Legal Defense Fund thank Mr. Wagener for using his voice to help the people we serve.

---

**Fair Game: Section 504 Provides Students with Disabilities Equal Access to Athletics & Other Extracurricular Activities**

By Kiernan Waters

Tyler is a college freshman who joined the school's lacrosse team after having played throughout high school. At practice, Tyler is one of the best players on the team, but the coach never plays him during games. The coach is aware of Tyler's epilepsy and assumes Tyler would be a danger to himself and his teammates during a game. Tyler takes an antiepileptic medication and has been seizure free for four years.

Eloise was inspired to try gymnastics after watching the winning 2012 Olympic Team. Her elementary school has an after-school gymnastics club that Eloise wants to join. As an insulin dependent diabetic, Eloise receives help from trained school personnel during the day, and would need this help after school in order to participate in the gymnastics club. The
school refuses to provide assistance to Eloise so that she can participate in the extracurricular activity.

Bethanny is an avid swimmer and just transferred to a public high school that has a champion swim team. Bethanny made the team and qualified to compete at the upcoming meet; however, the school district refuses to let Bethanny compete because she cannot complete the two hand touch required at the end of the race. Bethanny was born with only one hand and is a student with a disability as defined by Section 504 of the Rehabilitation Act of 1973.

Instances like these are happening across the United States and students with disabilities are being excluded from extracurricular athletic opportunities that provide important health and social benefits, such as socialization, teamwork, leadership skills, and fitness. To ensure that students with disabilities are given an equal opportunity to participate in extracurricular athletics, the United States Government Accountability Office (GAO) recommended that the Department of Education clarify the schools' responsibilities under Section 504 of the Rehabilitation Act of 1973, which is enforced by the Department of Education's Office of Civil Rights (OCR). This federal law was designed to protect disabled students from assumptions, stereotypes and inequality in programs and activities that receive federal funding. Section 504 requires that schools provide an equal opportunity for participation in nonacademic and extracurricular activities or provide for separate or different athletic opportunities.

Section 504 requires a school to include a student with a disability, as long as the student is qualified and meets the level of skill or ability necessary to participate in a competitive program. A school cannot deny a qualified student the opportunity to participate. Therefore, Tyler, Bethanny and Eloise are each being discriminated against in violation of Section 504. For Tyler, his coach's assumptions about the dangers of his epilepsy are a violation of Section 504 and the coach's decision of who plays in the game must be based on the same criteria used for all players. Bethanny's swim team requires two hand touch should be modified under Section 504 to allow her to participate with a one hand touch since this does not alter the fundamental nature of the activity. Likewise, under Section 504, Eloise must be provided with the assistance she needs to participate in the gymnastics club because the school is required to provide aid or services to students with disabilities to allow them equal opportunity to participate in extracurricular activities.

Students with disabilities that are not eligible to participate or cannot be accommodated through modification, aids, or services are also provided with equal opportunity to receive the benefits of extracurricular activities under Section 504. This means a school is required to offer separate or different athletic programs from those offered to students without disabilities and these should be equally supported by the school. This requires flexibility on part of the school to create unified teams of disabled and nondisabled students, co-ed teams, and district or regional teams.

"Participation in extracurricular athletics can be a critical part of a student's overall educational experience," said Seth Galanter, Acting Assistant Secretary for the OCR. "Schools must ensure equal access to that rewarding experience for students with disabilities." The OCR, in addition to ensuring equal access and opportunity for students with disabilities, also enforces Title VI of the Civil Rights Act of 1964 (which prohibits discrimination on the basis of race, color, and national origin in programs and activities that receive federal financial assistance), Title IX of the Education Amendment Act of 1972 (which prohibits discrimination on the basis of sex in educational institutions that receive financial aid), and Title II of the Americans with Disabilities Act (which prohibits disability discrimination by all public entities at the local and state level).

The Legal Defense Funds Helps File & Resolve Discrimination Cases

By Cherree Sanders

The following are recent cases which the Fund is monitoring or has provided support to attorneys representing people with epilepsy. 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 Cases

- **In re: R.M.** -- Mr. M. received an offer of employment from a California police department; however, the offer was withdrawn due to his history of seizures. He was evaluated by the employer's doctor, who determined that he was a high risk for seizure recurrence. He has only had two seizures in his life and has remained seizure free for over 10 years. A Legal Defense Fund attorney assisted the client by providing legal advice with navigating the employment process. The employer extended an offer of employment for Mr. M to work in a civilian role, which he accepted and also extended him an offer to join the next Academy class contingent on his passing of a neurological assessment.

- **In re: T.H.** -- Mr. H. was terminated after experiencing a seizure while in route to work. His employer terminated him from his position as a Crew Leader despite his doctor's authorization clearing him to return for work with recommendations of certain
accommodations (i.e., wearing a safety harness and temporary driving restriction). The employer also challenged his request for unemployment benefits. A Legal Defense Fund attorney is providing legal assistance with filing a charge of discrimination and helped Mr. H. appeal the denial of unemployment benefits. The decision to deny unemployment benefits was overturned. The charge of discrimination is still pending.

- In re: S.R: Mr. R was terminated from his position as a Preschool Teacher at an Early Learning Center after a new Director was hired. Under the previous Director, reasonable accommodations were in place to address his health condition (i.e., a safety plan and classroom aide). He was harassed and subsequently terminated. A Legal Defense Fund attorney assisted Mr. R. with filing a charge of discrimination with the EEOC. An investigation is pending.

- In re: R.H.: Mr. H. was employed as an Architectural Designer. He alleges that his employer terminated him after learning he has epilepsy. His employer alleges performance issues. A Legal Defense Fund attorney assisted Mr. H. with filing a charge of discrimination with his state’s civil rights agency, which is conducting an investigation. An investigation hearing was held and the parties are awaiting a determination.

- In re: C.C.: Mr. C. was employed as a Detention Officer. His seizures were well-controlled for several years. In 2012, Mr. C. experienced two breakthrough seizures as a result of changes to his work shift. He requested an accommodation to work during the day shift. The following day, he was terminated. A Legal Defense Fund attorney assisted Mr. C. with filing a charge of discrimination with the EEOC. An investigation is pending.

Arrest for Seizure Related Behavior
- In re: R.L.: Mr. L experienced a seizure while walking down the street in his community. A bystander called 911. Police officers who arrived on the scene assumed Mr. L was under the influence of drugs or alcohol. Officers beat him and shot him with a taser. He was arrested and charged with resisting arrest, public intoxication and other felony and misdemeanor charges. With the help of legal resources and a medical expert provided by the Fund, his attorney successfully negotiated a dismissal of the criminal charges. Mr. L. has obtained a civil attorney, who filed a lawsuit against the police department and arresting officers.

- In re: J.K.: While experiencing a complex partial seizure at a shopping mall, Mr. K picked up a two year old child and walked a short distance away from the toddler’s family. He was charged with attempted kidnapping. The Legal Defense Fund assisted his attorney with legal resources to share with prosecutors. Mr. K’s doctor also provided medical records and a letter of support. After considering this information, the State’s Attorney agreed to a dismissal of the charge. Mr. K’s medical condition will continue to be monitored by the District Attorney’s Office for the next few years to assure continued medical compliance.

Public Accommodation
- In re: J.H.: J.H. was denied service by a private taxi cab company after the company came under new management. J.H. used the cab service for several years prior to the new management. The company asserts that J.H. is a safety risk because he has epilepsy. A Legal Defense Fund attorney is providing legal assistance.

Other Cases of Interest:
- Galindo v. Reeves County, etc. 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 upon his arrival. After his arrival, his medication was switched from Topamax to Dilantin, which is a less expensive anti-seizure 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 that 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. A civil lawsuit was filed by his family and the case was settled. The terms of the settlement are confidential. A copy of the complaint can be viewed in the Legal Defense Fund’s Attorney Brief Bank.

Federal Motor Carrier Safety Administration Grants Exemptions to Epilepsy Drivers

By Gabrielle Lincoff

In January 2013, the Federal Motor Carrier Safety Administration ("FMCSA") within the U.S. Department of Transportation ("DOT") released a notice of final disposition (Fed Reg. Vol. 78. No. 10) on
applications for exemptions from the DOT regulation regarding commercial drivers with a history of seizures or epilepsy. The regulation (49 CFR 391.41(b)(8)), requires that an individual not have an “established medical history or clinical diagnosis of epilepsy or any other condition which is likely to cause loss of consciousness or any loss of ability to control a commercial motor vehicle.” This standard resulted in numerous drivers being prohibited from operating commercial motor vehicles (“CMV”) in interstate commerce if they had one or more seizures and were prescribed anti-seizure medication. The standard did not allow for individual assessments of a driver’s medical condition by a qualified medical examiner. After careful consideration, the agency concluded that granting exemptions for 22 CMV drivers with a history of seizures or epilepsy (and whose health conditions are well-controlled) will provide a level of safety that is equivalent to or greater than the level of safety maintained without the exemptions. The FMCSA exemptions will allow these 22 individuals to operate CMVs in interstate commerce for a 2-year period.

In 2006, the Epilepsy Foundation submitted a letter expressing concerns about the current regulation and its blanket exclusions for people with epilepsy or a history of recurrent seizures. The Foundation asserted the Americans with Disabilities Act and Section 504 of the Rehabilitation Act require individualized assessments of fitness and risks and prohibits blanket exclusions. Furthermore, the Foundation called for guidelines to reflect new developments in medicine and epilepsy treatments, and to consider an individual’s level of risk to public safety.

The FMCSA acknowledged the Foundation’s call for a thorough scientific-based reviewing process for considering exemption applications of CMV drivers with epilepsy. See, Fall 2006 Issue of the Legal Defense Fund newsletter at www.epilepsylegal.org.

As a result of the Foundation’s input, the FMCSA conducted a comprehensive literature review and gathered a panel of medical experts in epilepsy and neurology (May 2007) to address key questions and make recommendations concerning new guidelines for CMV drivers with the goal of ensuring minimal safety risk to the driver and public.

The recommendations of the medical expert panel and the scientific literature review were considered in the approval of the 22 exemption applications (submitted from 2006 to 2011). http://www.fmcsa.dot.gov/rules-regulations/topics/mep/mep-reports.htm for the evidence report and recommendations.

Comparing the Educational Rights of Public School Students to the Educational Rights of Parentally Placed Private School Students

By Wesley Garlick, Esq.

A student’s educational rights and legal protections are greatly affected by the type of school in which that student is enrolled. A student who is enrolled within the public school system has a much different set of educational rights as compared to a student who has been parentally placed within a private educational setting.

Traditional public schools are government operated and funded institutions. Being that these schools receive federal funding, they are required to follow federal regulations and mandates. With regard to special education rights and protections, the Individuals with Disabilities Education Act (“IDEA”) is the primary federal law governing public schools. The IDEA requires that each child be provided with a Free and Appropriate Public Education (“FAPE”). The IDEA defines FAPE as follows: special education and related services that (a) have been provided at public expense; (b) meet the standards of the State educational agency; (c) include an appropriate preschool, elementary school, or secondary school education; and (d) are provided in conformity with the individualized education.

Additionally, the term “related services” includes transportation and such developmental, corrective, and other supportive services as may be required to assist a child to benefit from special education. These services can include occupational therapy, physical therapy, language and speech services, and behavior intervention services among others. Often times these services can greatly assist special education students in making substantive academic progress.

The Supreme Court has aided in interpreting what does and does not qualify as a FAPE. In Rowley, the United States Supreme Court provided the following: “implicit in the congressional purpose of providing a ‘free appropriate public education’ is the requirement that the education provided be sufficient to confer some educational benefit upon the handicapped child.” Subsequently, federal courts have interpreted the Rowley standard in a way such that de minimus benefit or only trivial advancement has been held to be insufficient to satisfy the Rowley standard of “some” benefit.

Additionally, in determining whether a district has offered a student a FAPE, the proper focus is on the adequacy of

1 20 U.S.C. §602(9).
4 Walczak v. Florida Union Sch. Dist., 142 F.3d 119, 130 (2d Cir. 1997).
the offer of placement. If the district’s proposed program reflects the student’s unique needs, provides some educational benefit, and comports with the IEP, then the district has offered a FAPE. If, however, a student fails to make progress within a reasonable period of time, the district must convene an IEP meeting to address the student’s lack of progress. A district’s continuation of inadequate services will almost certainly be regarded as a denial of FAPE. On the other hand, private schools are generally funded through the tuition of their students and do not receive federal funding; because of this they are not bound by the same federal laws and regulations as public schools. Specifically, with regard to the providing of special education services, private educational institutions are not bound by the requirements of the IDEA.

With that said, the IDEA does require all Local Education Agencies (LEA) to apportion a specific amount of their IDEA funding to be used to provide special education services to children who have been parentally placed. With that said, the IDEA does require all Local Education Agencies (LEA) to apportion a specific amount of their IDEA funding to be used to provide special education services to children who have been parentally placed.

With that said, the IDEA does require all Local Education Agencies (LEA) to apportion a specific amount of their IDEA funding to be used to provide special education services to children who have been parentally placed.

5. Gregory K. v. Longview School District, 811 F.2d 1310, 1314 (9th Cir. 1987).
6. Id. at 1314.
7. 34 C.F.R. § 300.324(b)(2)(A).

Other News

- The Fund congratulates Gabrielle Lincoff, Law Clerk. Gabrielle has served as law clerk for the Foundation intermittently for the past two years. After graduation from the George Washington University Law School in May 2013, Gabrielle will be joining the George Washington University Office of the General Counsel as the Attorney Fellow.

While at the Foundation, Gabrielle worked on a wide variety of issues, including state licensing laws, service animals, ADA interpretation and litigation, implementation of the Affordable Care Act, proposed federal regulations, and individual consumer cases, to name a few. "We wish her the best of luck in her future endeavors!"

- In February 2013, the Fund participated in the University of Maryland’s Carey’s Law Public Interest Career Fair. More than 50 potential employers met with approximately 150 students, resulting in an excellent networking event between those interested in attaining and hiring public interest positions. Representatives of the Fund spoke with and collected resumes from many students interested in disability and health care law and also connected with many other public interest legal service associations in the area.

- In recognition of National Epilepsy Awareness Month, the Epilepsy Foundation and Disneyland Resort are teaming up to create a magical experience for families impacted by epilepsy. The inaugural Epilepsy Awareness Day at Disneyland Resort will take place on Thursday, November 7, 2013, as "The Happiest Place on Earth" honors people impacted by a medical condition for the first time. Attendees can purchase tickets on EpilepsyAwarenessDay.org with a designated portion of the ticket price supporting a 501(c)3 charity dedicated to helping people who live with epilepsy. Attendees will also receive a gift bag which includes a special event T-shirt and other materials.

9. 34 CFR §300.132.
10. 34 CFR §300.134.
11. 34 CFR § 300.141.
12. 34 C.F.R. § 300.138(b).
13. 34 CFR §300.137(a).
provide adequate notice of their rejection of the district’s proposed inappropriate offer of FAPE and of their intent to unilaterally place their child within a private educational setting at the public’s expense. This notice can effectively be communicated at the student’s IEP meeting, or may be provided in writing 10 business days prior to removal of the child.¹⁵

In conclusion, there are a number of reasons why a parent may prefer to place their child in a private educational setting. However, it is important to note that in choosing to remove their child from a public school setting, they are also forfeiting many of the educational protections offered under the IDEA, including the right to a FAPE.

**California Insulin Ruling Opens Doors**  
*By Brian Fiske*

The California Supreme Court recently ruled that school personnel can volunteer and be trained to help children administer insulin in school. This is a great victory for students living with diabetes, especially with many schools unable to afford a full time nurse, but the implications of the ruling reach even further than the diabetes community.

The ruling states “we conclude the medical—orders exception does permit a layperson to carry out a physician’s medical orders for a patient, even orders that would otherwise fall within the definition of nursing practice, without thereby violating the rule against unauthorized practice,” and that only by portraying oneself to be a nurse either implicitly or explicitly would a person “fall outside the exception.” We believe that this ruling opens the doors for school personnel or personnel of licensed care facilities, IHSS workers, and others to administer care to those living with a disability in a way that will allow them to continue to live independent and full lives.

Now that the ruling has been sent back to the 3rd District Court of Appeal for further proceedings based on the published opinion we will continue to follow it and look for opportunities to implement beneficial changes for those living with epilepsy in California.

**Convention on the Rights of Persons with Disabilities**  
*By Brian Fiske*

During the 112th Congress, the Convention on the Rights of Persons with Disabilities (CRPD) suffered an unfortunate setback as ratification failed by only six votes. However, the Foundation is working diligently to get the CRPD reintroduced and ratified. The treaty is designed to ensure equal rights for those living with disabilities, including epilepsy, throughout the world. The CRPD was based off of the Americans with Disabilities Act and reflects the United States leadership in the area of disability rights. The CRPD is consistent with U.S. laws and has already been ratified by 133 countries, including important U.S. allies. If the U.S. does not ratify the CRPD, the nation risks losing its position as a leader in disability rights.

The nation would also be risking the rights of all U.S. citizens living with disabilities throughout the world. To take action please visit http://capwiz.com/efa/issues/ and contact your state’s senators to express your support for the CRPD.

**Fund Seeks Attorneys to Join its Legal Advocacy Network**  

Every day someone faces discrimination because he or she has epilepsy or seizures, and too often competent legal assistance is unavailable. The Fund is seeking to expand its growing network of cooperating attorneys (both those with or without experience in disability law are welcome) to provide critically needed help to fight discrimination against people with epilepsy. 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.

Individual attorneys may register on-line directly from the Fund’s website to start receiving case referrals. Simply go to www.epilepsylegal.org, click on “Apply to Join Our Network” and provide the requested information. Soon after a registration is completed, the Fund sends out a welcome package, with resources and background information.

¹⁵ 20 U.S.C. §1412
Resources for Attorneys

**Brief Bank.** The Fund has added new briefs to its brief bank, which may be accessed by cooperating attorneys. In particular, a number of litigation documents were added to the First Responder/Seizure Management and Employment sections. To access the brief bank, go to www.epilepsylegal.org and click on “Attorney Resources.” To login, it will then be necessary to enter your user name and password, which were created when registering as a cooperating attorney. (If you do not have access to this information, you can send an email to ldfsupport@efa.org to request new login credentials.) We would appreciate receiving your briefs and other litigation documents (e.g., complaints, discovery documents, jury instructions, etc.) on epilepsy-related discrimination cases – so we can add them to the brief bank for the benefit of all. Please send these materials to legalrights@efa.org.

**Reminder: Legal Defense Fund Listserv**

The Fund has established a listserv through YahooGroups for its cooperating attorneys and other attorneys handling epilepsy discrimination cases. The purpose of the listserv is to provide a forum for participants to share information and resources to help fight discrimination against people with epilepsy in employment, education, the criminal justice system, public services and other areas. The listserv will also be used to provide updates on developments in related areas of the law and policy. Moreover, participants can let their peers know about epilepsy-related case developments (including victories and defeats) and useful strategies – and questions that arise as cases are pursued. Attorneys who are interested in joining the listserv should contact legalrights@efa.org.

**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 website, 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.

Attorneys: Attorneys representing people experiencing epilepsy-related discrimination may contact the Fund for assistance by email (legalrights@efa.org) or by calling 301-459-3700, ext. 3767. The Fund can provide a variety of resources such as: legal research, briefs, case lists, expert referrals, and medical information.