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

Jeanne A. Carpenter
Epilepsy Legal Defense Fund
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Back to School — Ensuring Equal Opportunities for Students with Epilepsy

The hundreds of thousands of children living with epilepsy are affected in a variety of ways. For some, it will be a temporary problem, easily controlled with medication and outgrown after a few years. For others, it may be a lifelong challenge affecting many areas of life. Medical treatment of childhood epilepsy is getting better, and research towards a cure continues. However, children with epilepsy, just like adults, continue to be subject to discrimination, particularly in school. For instance, schools may refuse to administer emergency medication for seizures, placing a child’s health at risk.

The following outlines the federal legal protections for students with epilepsy, along with information on helpful resources the Fund makes available for parents and attorneys and some suggested advocacy tips for parents.

The Individuals with Disabilities Education Act (IDEA) is the main law that governs special education for students with disabilities. If students with epilepsy have trouble making educational progress because of their condition, they can qualify for special education services under this law. The IDEA sets out a framework for referring and testing students for special education, identifying them as having disabilities that have an adverse impact on their ability to benefit from education, developing an individualized education program (IEP), placing them into special education, and reviewing their placements on a regular basis. The law contains a number of requirements designed to protect the rights of children and parents in the special education process.

If students with epilepsy need special education, they are entitled to IEPs that set out the special education and any related services they will receive, which are necessary to educate the child. (Related services are corrective and other supportive services that are needed to assist a child with a disability to benefit from special education. Such services may include speech-language or physical therapy and school health services.) The IEP must be implemented in the least restrictive environment in which the student’s needs can be met. This means that, to the greatest extent possible, a student with disabilities must be placed in general education and that supports and services are to be provided to make this placement successful.

Only if a student cannot successfully be placed in the general

continued on p. 2
If your child needs medication, either routine or emergency, this should be listed on the IEP or section 504 plan, with the dosage, the times it is to be given and the person identified who will give it.

A model Section 504 plan is set out in the Epilepsy Foundation’s manual on advocating for the rights of children in school and child care.

For these students, a Section 504 plan would be appropriate. The plan would set out the reasonable accommodations to be provided to the student on the basis of his or her epilepsy. (A model Section 504 for students with epilepsy is set out in the Epilepsy Foundation’s manual on advocating for the rights of children in school and child care – see information on resources.)

The Americans with Disabilities Act (ADA) provides to students with epilepsy in private schools rights which are comparable to those enjoyed in public schools. They have the right to reasonable accommodations that do not fundamentally alter the program, if the school is subject to the ADA.

Below are some general advocacy tips, reprinted from our Education and Day Care brochure.

Advocacy Tips

1. Know the rights that you and your child have in the special education process and under Section 504. A basic understanding of the law will help you as your child progresses through his school years.

2. Be clear about whether you are seeking special education under the IDEA or services or accommodations under Section 504. Does your child need specially designed special education and related services in order to make educational progress? If so, you will want to advocate for special education and an IEP. Can your child succeed in general education with some accommodations for his epilepsy?

3. If your child needs medication, either routine or emergency, this should be listed on the IEP or section 504 plan, with the dosage, the times it is to be given and the person identified who will give it.

If a health plan or a seizure management plan is developed for your child with this administration of routine antiseizure medication or emergency medication such as rectally administered diazepam (sold under the brand name Diastat AcuDial), extra time for tests (seizures or medication side effects may interfere with tests), or reduced workloads during medication adjustments. For these students, a Section 504 plan would be appropriate. The plan would set out the reasonable accommodations to be provided to the student on the basis of his or her epilepsy. (A model Section 504 for students with epilepsy is set out in the Epilepsy Foundation’s manual on advocating for the rights of children in school and child care – see information on resources.)

The Fund has been advocating, along with the Foundation’s affiliates, to ensure that children with epilepsy have equal educational opportunities.

- Parents of children with epilepsy who have concerns or questions about these issues are invited to contact the Fund for information and referrals to attorneys, if appropriate – go to the Fund’s website, www.epilepsylegal.org, or call 1-800-332-1000

- For general information about epilepsy and its treatment and how the Epilepsy Foundation’s affiliates can help, contact the Foundation at the same number or go to www.epilepsyfoundation.org

- Resources to assist parents of children with epilepsy self-advocate for school services (as well as services in child care programs) may be downloaded from the Fund’s website at www.epilepsylegal.org – go to “Legal Information Center” and then click on “Legal Fact Sheets.” In particular, see our brochure, Education and Day Care: Advocating for Your Child, and our detailed manual, Legal Rights of Children with Epilepsy in School and Child Care: An Advocate’s Manual

- Also see www.epilepsyclassroom.com, the Foundation’s compilation of materials for teachers and parents on managing epilepsy in the classroom

- Resources to Fight Discrimination in Schools and Advocacy Tips

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What absolutely needs to be in the IEP or Section 504 plan.

4. Prioritize what you want for your child before you go to an IEP or Section 504 meeting:
   - What absolutely needs to be in the IEP or Section 504 plan?
   - What would you like to have in the document, but are you willing to compromise on?
   - For the items you feel are necessary, be sure to adequately justify your position. Do you have evaluations or other documentation recommending the services you believe are necessary for your child? What is the position of your child’s teacher or other professionals at the school? If you do not have support for your position, consider moving the item into a lower-priority category or giving it up for the time being.

5. Make use of advocacy resources. No parent can be an expert in all areas. You may feel you are expected to learn everything about epilepsy, medications and their side effects, insurance or Medicaid, the ADA and special education law. In fact, while it is helpful to have enough knowledge to understand how the systems work and to know what questions to ask, you do not have to do this all by yourself. You can obtain many helpful resources from the Epilepsy Foundation and its local affiliates (see above).

The Medical Board of the Police Pension Fund terminated Mr. Fletcher’s employment without conducting an individualized medical assessment. Mr. Fletcher, whose job performance had consistently been excellent, was terminated despite the fact that he had only experienced nocturnal seizures (on a very infrequent basis) and had been cleared for full duty by his neurologist. The case is currently in discovery.

**Action Challenging Rejection of Firefighter Applicant based on NFPA Standards – In re A.B.** An Iowa fire department rejected A.B.’s application for a firefighter position, relying on the medical qualification standards established by the National Fire Protection Association (NFPA). These standards recommend that firefighter applicants with epilepsy be seizure-free without medication for five years. A discrimination charge was filed with the Iowa Civil Rights Commission, which issued an administrative closure notice in July, concluding that A.B. was not qualified for the position. A.B.’s attorney is administratively appealing this determination.

**Rejection of Surgical Technician Applicant – Brandt v. University of Colorado Hospital (filed D. Co. 2011).** Brandt was denied a position as a surgical technician with the hospital after disclosing her medical history of seizures. Ms. Brandt’s seizures are infrequent and well-controlled with medication and she had been able to perform successfully in similar positions prior to her rejection. **Nicholas J. Enoch**, a Fund network attorney, filed an ADA action, and an excellent brief in opposition to the hospital’s motion for summary judgment (available on the Fund’s brief bank). The motion, which raised safety-related arguments in support of the rejection, is pending.

**Disqualification Based on Ineligibility for DOT Interstate Driving Certificate – EEOC v. Georgia Power Co. (N.D. Ga.).** In June, the EEOC entered into a consent decree under which Garney Construction Co. and Georgia Power Company will pay $49,500 and furnish other relief to settle a case in which a heavy equipment operator with epilepsy was disqualified based on his ineligibility for a U.S. Department of Transportation medical certification to drive trucks interstate. In this case, Garney offered a front-end loader job to Mr. Mimmovich (who was represented by Fund network attorney **Doug Carter**, who intervened in the action on Mimmovich’s behalf) at its construction site at the Georgia Power plant in Juliette, Georgia. Garney required Mimmovich to obtain a DOT medical certification to operate a “commercial motor vehicle” (one weighing in excess of 10,000 pounds which is driven across state lines). DOT regulations provide that anyone with a history of seizures or who is on antiseizure medication is ineligible for the medical certification. Because Mimmovich was on antiseizure medication, he was found ineligible for the certificate and denied the job – notwithstanding the fact that federal law does not...
require heavy equipment operators to qualify for the medical certification, and at the time he applied for the job, Mimmovich had been seizure-free for over eight years.

The EEOC’s lawsuit charged that Garney failed to hire Mimmovich because of his disability and that Georgia Power interfered with Mimmovich’s employment relationship with Garney by requiring Garney to refuse to hire him because of his disability without an individualized assessment of his ability to perform the job.

**Disqualification Based on Ineligibility for DOT Interstate Driving Certificate – Whitehead v. UPS (N.D.N.Y.).** In an action filed by Fund network attorneys John Griffin and Kathy Butler, a confidential settlement was reached in January with UPS regarding its rejection of Mr. Whitehead, a truck mechanic, whom UPS terminated from that position because he could not qualify for a DOT medical certificate to drive trucks interstate. It became clear during the case that Mr. Whitehead’s mechanic position did not involve driving commercial motor vehicles in interstate commerce, and therefore, he did not need to possess a DOT medical certificate. The action was filed after the EEOC issued a finding that UPS’s policy violated the ADA. The Fund provided legal support and a small grant to help defray the costs of discovery.

During the course of the litigation, Mr. Whitehead’s counsel received from DOT an opinion letter (addressing the facts in the case) indicating that interstate commerce is determined by the shipper’s intent and a package vehicle carrying no cargo that is test driven by a mechanic within one state (New York) is operated in “intrastate, not interstate, commerce.” Accordingly, the driver of such a vehicle would not be obligated under DOT regulations to obtain a medical certificate. DOT’s opinion letter is available on the Fund’s brief bank.

**Other Cases of Interest**

**Sixth Circuit Affirms Need for Individualized Assessment Before Transferring Student with a Disability to Non-neighborhood School for Nursing Care – R.K., et al. v. Board. of Educ. of Scott County, Kentucky, 2012 U.S. App. LEXIS 17386 (6th Cir. Aug. 16, 2012).** R.K., a student with diabetes who requires administration of insulin during the school day, alleged that the school board violated the ADA. The Fund provided legal support and a small grant to help defray the costs of discovery. The Sixth Circuit decision was positively influenced by the terrific amicus briefs filed by the Department of Justice (available at http://www.ada.gov/briefs/rk_amicus_brief.pdf) and the American Diabetes Association (available at http://www.ada.gov/briefs/rk_amicus_brief.pdf).

This case is a very positive development for students with epilepsy who may need to have emergency antiseizure medication administered during the school day or extracurricular activities. It underscores the fact that school districts seeking to transfer such students to receive nursing care – which may remove a child to a distant school away from siblings and friends – must show that they conducted an adequate individualized assessment regarding the need for the transfer and complied with the other Section 504 mandates highlighted by the court.

**Justice Department Enters Settlement with Baltimore County Protecting the Rights of Workers with Epilepsy and other Disabilities – U.S. v. Baltimore County, Maryland (D. Md. August 7, 2012).** The Justice Department filed a complaint in the U.S. District Court for the District of Maryland alleging that Baltimore County has engaged in a pattern and practice of discrimination in violation of the ADA, along with a consent decree to settle the case. The complaint alleged that the County was requiring certain employees to submit to medical examinations and disability-related inquiries without a proper reason, and was excluding certain applicants from emergency medical technician positions because of their disabilities.

Under the settlement, the county will be required to pay $475,000 to ten County employees with disabilities, including a man who was discriminated against because he experienced a seizure. It also requires the County to institute many reforms to ensure its employment practices comply with the ADA. The Justice Department was prompted in part to conduct the investigation of the County’s employment practices that lead to this settlement by information provided about apparent discrimination against County police officers with epilepsy by the Fund and Kathleen Cahill, a prominent Towson, Maryland employment discrimination attorney, and a member of the Fund’s Legal Advisory Board.
The consent decree is available at http://www.ada.gov/baltimore_co_cd/baltimore_co_CD.htm.

**Fund Recognizes Advocacy and Philanthropy of Leslie Seid Margolis**

We are grateful to Leslie Seid Margolis, a nationally recognized expert on special education and a cooperating attorney with the Legal Defense Fund, for her advocacy on behalf of people with epilepsy – as well as for her philanthropy benefitting the Defense Fund. Leslie has devoted her career to special education litigation and public policy reform benefitting people with disabilities. She currently serves as the Managing Attorney for the Education Unit at the Maryland Disability Law Center in Baltimore, where she supervises attorneys and paralegals, and provides legal representation in special education cases. She has authored numerous publications on topics related to special education, including a fabulous manual for the Epilepsy Foundation, *Legal Rights of Students with Epilepsy in School and Child Care: An Advocate’s Manual* (available at http://www.epilepsyfoundation.org/resources/epilepsy/legal/legal-fact-sheets.cfm). Leslie has also been a presenter at numerous seminars and training sessions throughout the country on various topics related to special education law and policy.

Leslie’s advocacy on behalf of people with epilepsy has been particularly helpful in ensuring access to emergency antiseizure medication in school and child care. In her first case in this area, she dealt with a school system which refused to provide a nurse to administer such medication and a school district nurse who refused to delegate the task to non-medical school staff. In a creative solution resolving the matter, a settlement was reached allowing the student’s doctor to delegate the authority to administer the medication directly to a trained non-medical school aide who worked with the child. In another case, Leslie represented the parents of a child who was denied admission to a local after-school program because she was prescribed Diastat (rectally administered valium) for prolonged seizures, and program staff refused to administer the medication. The case resolved, with the program agreeing to admit the child and provide appropriate care. Leslie is currently working on another similar case, involving a child denied admission to a camp.

In May 2009, Leslie joined the Epilepsy Foundation’s Board of Directors, and has recently become the Chair of the Legal Defense Fund’s Legal Advisory Board. In addition, Leslie serves on the boards of other disability rights advocacy organizations, including the Council of Parent Attorneys and Advocates (COPAA) and Children and Adults with Attention Deficit Disorders of Greater Baltimore. She is also Founder and Chair of the Education Advocacy Coalition for Students with Disabilities, which is a coalition of disability and education organizations that addresses regulatory, legislative, and other policy issues throughout Maryland. Leslie is a graduate of Princeton University and Stanford Law School.

In addition to being an accomplished attorney, Leslie is a devoted wife and mother of two daughters. Just recently, her family celebrated the 18th birthday of her older daughter, Paz, who was born with lissencephaly, a rare genetic brain disorder that results in profound developmental disabilities and difficult to control seizures. Her 18th birthday was a momentous occasion for the family and it inspired Leslie and her husband Russell Margolis, M.D., to host a fundraising event at their home for the benefit of the Legal Defense Fund and the local Epilepsy Foundation affiliate. Family members and many friends donated generously. In an especially thoughtful and generous gesture, Leslie and Russell personally matched the contributions. (An equal amount was donated to another disability rights organization.)

In Leslie’s spare time, when she is not driving her 13 year old daughter to the Target for yet one more thing they forgot to buy when they were last out, she is a serious amateur flutist.

The Fund applauds Leslie for her strong leadership in the fight to prevent discrimination against people with epilepsy and other disabilities.

**California’s School Emergency Antiseizure Medication Regulations Go into Effect**

Thanks largely to the fabulous advocacy work of the Epilepsy Foundation affiliates in California, new final regulations recently went into effect to help ensure that California’s 93,000 students with epilepsy will have immediate access to emergency antiseizure medication in school. The regulations authorize school districts, county offices of education, and charter schools to participate in a program to provide nonmedical school employees with voluntary emergency medical training to administer emergency antiseizure medication, including rectally administered diazepam (sold under the brand name Diastat AcuDial) to pupils with epilepsy. The regulations specify that the medication may be administered in the absence of a credentialed school nurse or other licensed nurse onsite at the school with continued on p. 6
a parent’s written authorization, and set out detailed provisions on training of school staff.

Senate Bill 161 (codified in California Education Code section 49414.7), the product of several years of legislative advocacy spearheaded by the California affiliates, authorized the issuance of these regulations – which provide a great model for other states.

Given that licensed health care personnel are frequently not available at many schools across California (the state’s nurse-to-student ratio is approximately 1:2,200), and that this medication can be safely administered by trained nonmedical school staff, the approach established by the legislation and the regulations is in the best interests of students with epilepsy. We commend state Senator Huff (the sponsor of the bill) and Governor Brown for their leadership on this issue. For detailed information on the requirements of other state laws relating to the administration of antiseizure medication in school, contact legalrights@efa.org.

**Justice Department Files Suit Seeking to Ensure Illinois Recreation Program Provides Access to Emergency Antiseizure Medication**

On September 24, the U.S. Department of Justice filed litigation under the Americans with Disabilities Act (ADA) against the Northern Illinois Special Recreation Association (NISRA) to ensure that people with epilepsy participating in its programs have immediate access to a potentially life-saving emergency antiseizure medication, diazepam rectal gel (*United States v. Northern Illinois Special Recreation Association*, N.D. Ill.). NISRA, which is formed from 13 park districts and municipal recreation departments in northern Illinois, provides year-round recreational opportunities for children and adults with disabilities such as therapeutic recreation, Special-Olympics training programs and summer camps. The Fund provided technical support to the Justice Department, including a referral to an expert, to help develop the case.

The lawsuit, apparently the first of its kind brought by the Justice Department, charges that NISRA refuses to allow its staff to administer this medication to M.M. and N.R., two children with epilepsy, who live in McHenry County, IL and Crystal Lake, IL, respectively, who want to attend summer camps run by NISRA. According to the Justice Department complaint, M.M. desperately wants to participate in future summer camps, because it is the only camp available to her. But she cannot do so, because NISRA’s refusal to administer the medication makes her participation very risky to her health. Similarly, N.R.’s participation in the camp program is also quite risky because of this policy.

Children with epilepsy are particularly susceptible to prolonged seizures that may cause serious brain injury or death if not promptly treated. Yet, NISRA’s only plan for both M.M. and N.R. was to call 911 in the event they experienced a prolonged seizure, which would result in a dangerous delay in treatment.

As the Justice Department suit states, under the ADA, which prohibits discrimination against people with epilepsy and other disabilities in recreational programs and other public accommodations, NISRA has an obligation to modify its policy against administering this medication. This policy change is necessary to afford M.M., N.R. and other children and adults with epilepsy an equal opportunity to participate in NISRA’s programs.

The Epilepsy Foundation commends the Justice Department for taking this action. A copy of the complaint in the case is available on the Fund’s brief bank.

**Largest U.S. Child Care Provider Successfully Implements Seizure Care Policy**

Since 2009, the largest corporate child care provider in the U.S., Knowledge Universe (KU), which operates KinderCare, Knowledge Beginnings child care centers and other child care providers, has been successfully implementing a comprehensive written policy on providing emergency antiseizure medication and other first aid to children with epilepsy. The policy, which was developed in collaboration with the Epilepsy Foundation (and is based largely on the Foundation’s model child care seizure disorder emergency treatment plan), helps ensure that children with epilepsy attending any of the company’s 2000 plus centers operated around the country are administered, as needed, both routine and emergency antiseizure medications. In administering medication and providing other care, child care center staff are required to follow a standardized seizure management plan. The plan is to incorporate specific instructions from the child’s parents and treating physician, including information on determining when to call 911 to respond to prolonged or repetitive seizures.

The policy further specifies that child care center staff will:

- Receive, as needed, appropriate training on administering emergency antiseizure medication – in many cases, the Foundation’s affiliates have provided the training.
• Follow any specified activity and dietary restrictions for the child
• Allow the child a reasonable rest period following a seizure to permit the child to recover and return to center activities, and
• Complete a seizure observation record and provide it the parents (and if necessary, to emergency medical personnel), allowing them to accurately track their child’s seizure activity

KU staff report that there have many instances of successful seizure response as a result of this policy and are very enthusiastic about its success. The policy is designed to maintain the safety of children in these programs, while avoiding unnecessary trips to the emergency room. The Foundation’s model child care disorder emergency treatment plan, upon which KU’s policy is largely based, is available in the Foundation’s Legal Rights of Children with Epilepsy in School & Child Care: An Advocate’s Manual (see appendix A), which may be accessed at www.epilepsylegal.org (click on “Legal Information Center” and see the education materials under “Legal Fact Sheets”).

Child care providers are strongly encouraged to follow KU’s lead and develop similar seizure management policies based on the Foundation’s model.

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. For instance, based on stereotyped views about epilepsy, employers frequently deny job opportunities to qualified workers with the condition. Schools may fail to ensure adequate accommodations for students with the condition, including access to emergency medication. And sometimes, law enforcement officers, misinterpreting behaviors associated with a seizure as combativeness or intoxication, respond with inappropriate force, causing serious injury or even death.

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 (see below). The Fund maintains a database on the practice areas of cooperating attorneys and the type of case referrals desired, and always limits referrals based on this information.

Individual attorneys 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.

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. 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: Attorneys representing persons experiencing epilepsy-related discrimination may contact the Fund for assistance via 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. In cases of national significance, we can consider filing or signing on to an amicus brief and/or providing a grant to help defray litigation costs.
**New Resources for Attorneys**

*Brief Bank Expanded.* The Fund has added a number of 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.

*Listserv Established.* The Fund has established a listserv through Yahoogroups for its cooperating attorneys and other attorneys handling epilepsy discrimination cases. In the near future, it will be expanded to include attorneys who work with other disability rights organizations and government agencies with a role in disability rights advocacy. 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. In the near future, the Fund’s cooperating attorneys will be receiving an invitation to join the listserv – and we encourage you to do so. Other attorneys who are interested in joining the listserv should contact legalrights@efa.org.

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**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, use our donation envelope (provided in the print version of the newsletter); go to our website, epilepsylegal.org, and click on “Make a Donation”; or scan this QR code with your smart phone and instantly go to the Fund’s donation page.

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