



www.EpilepsyCalifornia.org

# Special California Edition 2008

## INTRODUCTION TO EPILEPSY CALIFORNIA

Epilepsy California is the recognized, unified voice of people with epilepsy throughout California. We are your resource when it comes to epilepsy in California.

We are here to represent the almost 400,000 people with epilepsy in our state. We hope that the information presented here will help to further educate you and your friends and family about epilepsy. The "Brain Wave Update" briefly highlights some of the issues that are important to us. Please keep this Epilepsy California newsletter for future reference.

We invite you to join Epilepsy California in making a difference for the almost 400,000 families affected by epilepsy. With your help, real change can happen and we can improve the lives of individuals with epilepsy.

Join us! Be an advocate. Sign up to receive information and to participate in grassroots advocacy on behalf of the epilepsy community in California. Visit [www.epilepsycalifornia.org](http://www.epilepsycalifornia.org)!

Sincerely,

Susan Pietsch-Escueta, Executive Director

Neva Hirschhorn, Executive Director

Kathy D. West, Executive Director



Epilepsy Foundation affiliate executive directors:  
Left to right: Susan Pietsch-Escueta, Greater Los Angeles; Neva Hirschhorn, Northern California; Kathy West, San Diego

## BRAIN WAVE UPDATE

### POLICY BRIEF – IMPORTANT POLICY ISSUES

#### **Access to Epilepsy Medication and Treatment**

It is essential for all people with epilepsy to have ready access to quality care that appropriately suits their individual needs. Epilepsy California must ensure a full range of medication and treatment types are available to those that require any level of care.

#### **Patient Protection**

To help prevent breakthrough seizures, Epilepsy California strongly encourages notification and informed consent of both patient and physicians before changing or replacing a patient's medication in any way. Antiepileptic drugs (AEDs) are very precise and establish a delicate balance for each individual with epilepsy. Any slight change to medications can cause breakthrough seizures. Because the therapeutic window is often very narrow for people with epilepsy it is critical that each individual have access to the medication that provides the best outcome for them.

**To further protect patients, Epilepsy California also encourages physicians to ensure that medications are dispensed as written by hand-writing their initials in the "Do Not Substitute" box or hand-writing "Do Not Substitute" on written prescriptions.**

#### **Access to Seizure Rescue Medications**

Individuals with prolonged or clustered seizures sometimes are prescribed an emergency seizure rescue medication to be administered by a caretaker. Current State laws and regulations are not consistent and prevent children in schools and adults in residential care facilities from receiving the medication. Epilepsy California seeks to work with State education and health groups to develop a life-saving plan that will support our students and our resident adults.

#### **Driving Laws**

Due to the varied nature of epilepsy, Epilepsy California opposes across-the-board seizure free requirements, and endorses individualized evaluations of one's ability to drive. California remains one of only six states that currently requires mandatory physician reporting. Epilepsy California will continue to support efforts to change state laws or regulation to reverse mandatory physician reporting.

#### **Civil Rights**

Epilepsy California promotes the expansion of civil rights laws to ensure that people with epilepsy have essential protections from discrimination based on disability in any part of life, especially in the workplace.



# Seizure Recognition and First Aid

SEIZURE TYPE	WHAT IT LOOKS LIKE	WHAT IT IS NOT	WHAT TO DO
<p><b>Generalized Tonic Clonic</b> (Also called Grand Mal)</p>	<p>Sudden cry, fall, rigidity, followed by muscle jerks, shallow breathing or temporarily suspended breathing, bluish skin, possible loss of bladder or bowel control, usually lasts a couple of minutes. Normal breathing then starts again. There may be some confusion and/or fatigue, followed by return to full consciousness.</p>	<p>Heart attack. Stroke.</p>	<p>Look for medical identification. Protect from nearby hazards. Loosen ties or shirt collars. Protect head from injury. Turn on side to keep airway clear unless injury exists. Reassure as consciousness returns. If single seizure lasted less than 5 minutes, ask if hospital evaluation wanted. If multiple seizures, or if one seizure lasts longer than 5 minutes, call an ambulance. If person is pregnant, injured, or diabetic, call for aid at once. (See also page 4.)</p>
<p><b>Absence</b> (Also called Petit Mal)</p>	<p>A blank stare, beginning and ending abruptly, lasting only a few seconds, most common in children. May be accompanied by rapid blinking, some chewing movements of the mouth. Child or adult is unaware of what's going on during the seizure, but quickly returns to full awareness once it has stopped. May result in learning difficulties if not recognized and treated.</p>	<p>Daydreaming. Lack of attention. Deliberate ignoring of adult instructions.</p>	<p>No first aid necessary, but if this is the first observation of the seizure(s), medical evaluation should be recommended.</p>
<p><b>Simple Partial</b></p>	<p>Jerking may begin in one area of body, arm, leg, or face. Can't be stopped, but patient stays awake and aware. Jerking may proceed from one area of the body to another, and sometimes spreads to become a convulsive seizure.</p> <p>Partial sensory seizures may not be obvious to an onlooker. Patient experiences a distorted environment. May see or hear things that aren't there, may feel unexplained fear, sadness, anger, or joy. May have nausea, experience odd smells, and have a generally "funny" feeling in the stomach.</p>	<p>Acting out, bizarre behavior. Hysteria. Mental illness. Psychosomatic illness. Parapsychological or mystical experience.</p>	<p>No first aid necessary unless seizure becomes convulsive, then first aid as above.  No immediate action needed other than reassurance and emotional support. Medical evaluation should be recommended.</p>
<p><b>Complex Partial</b> (Also called Psychomotor or Temporal Lobe)</p>	<p>Usually starts with blank stare, followed by chewing, followed by random activity. Person appears unaware of surroundings, may seem dazed and mumble. Unresponsive. Actions clumsy, not directed. May pick at clothing, pick up objects, try to take clothes off. May run, appear afraid. May struggle or flail at restraint. Once pattern established, same set of actions usually occur with each seizure. Lasts a few minutes, but post-seizure confusion can last substantially longer. No memory of what happened during seizure period.</p>	<p>Drunkenness. Intoxication on drugs. Mental illness. Disorderly conduct.</p>	<p>Speak calmly and reassuringly to patient and others. Guide gently away from obvious hazards. Stay with person until completely aware of environment. Offer to help getting home.</p>
<p><b>Atonic Seizures</b> (Also called Drop Attacks)</p>	<p>A child or adult suddenly collapses and falls. After 10 seconds to a minute he recovers, regains consciousness, and can stand and walk again.</p>	<p>Clumsiness. Normal childhood "stage." In a child, lack of good walking skills. In an adult, drunkenness, acute illness.</p>	<p>No first aid needed (unless he hurt himself as he fell), but the child should be given a thorough medical evaluation.</p>
<p><b>Myoclonic Seizures</b></p>	<p>Sudden brief, massive muscle jerks that may involve the whole body or parts of the body. May cause person to spill what they were holding or fall off a chair.</p>	<p>Clumsiness Poor coordination.</p>	<p>No first aid needed, but should be given a thorough medical evaluation.</p>
<p><b>Infantile Spasms</b></p>	<p>These are clusters of quick, sudden movements that start between 3 months and two years. If a child is sitting up, the head will fall forward, and the arms will flex forward. If lying down, the knees will be drawn up, with arms and head flexed forward as if the baby is reaching for support.</p>	<p>Normal movements of the baby. Colic</p>	<p>No first aid, but doctor should be consulted.</p>

# Medicines for Epilepsy

This chart is designed to help people with epilepsy (seizure disorders) become more familiar with the medications they are taking. It is not designed for use by health or other professionals to identify drugs. The list includes drugs that are sometimes prescribed for epilepsy, but not FDA-approved for that use. Other drugs not listed here may also be prescribed to prevent seizures.

The pictures are of brand name drugs as of the printing date. However, drugs may change in appearance from time to time. Generic versions of these drugs (listed in italics, under the brand name) will look different from the brand name drugs. Drugs shown below are not actual size.

The list of side effects is not complete because of space limitations. For a complete list, consult your doctor, nurse, or pharmacist. More detailed sources of information on side effects include the drug's prescribing information sheet, or the Physician's Desk Reference.

Any change in physical or mental health in someone taking these medications should be reported promptly to the doctor. Safety in pregnancy has not been established for any of these medications. Questions about their use in pregnancy should be discussed with the doctor.

FORM (of brand name product)	BRAND NAME (generic name)	AVERAGE ADULT DAILY DOSE <small>Actual doses for a person with epilepsy may be higher or lower than the doses listed.</small>	SOME SIDE EFFECTS <small>Not all individuals experience side effects. This partial list names some side effects individuals may experience.</small>
	*ATTIVAN® ( <i>lorazepam</i> )	1 mg. – 10 mg.	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes
	CARBATROL® ( <i>extended release carbamazepine</i> )	600 mg. – 1200 mg.	Dizziness, drowsiness, blurred or double vision, nausea, skin rashes, abnormal blood counts (rare)
	DEPAKENE® ( <i>valproate</i> )	1750 mg. – 3000 mg.	Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor
	DEPAKOTE® ( <i>divalproex sodium</i> )	1750 mg. – 3000 mg.	Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor
	DEPAKOTE® ER ( <i>extended release divalproex sodium</i> )	2000 mg. – 3500 mg.	Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor
	DIAMOX® ( <i>acetazolamide</i> )	250 mg. – 1000 mg.	Appetite loss, frequent urination, drowsiness, confusion, numbness of extremities, kidney stones
	DILANTIN® ( <i>phenytoin</i> )	200 mg. – 400 mg.	Clumsiness, insomnia, motor twitching, nausea, rash, gum overgrowth, hairiness, thickening of features
	FELBATOL® ( <i>felbamate</i> )	1200 mg. – 3600 mg.	Anorexia, vomiting, insomnia, nausea, headache, liver and blood toxicity
	GABITRIL® ( <i>tiagabine</i> )	32 mg. – 56 mg.	Tremor, dizziness, nervousness, difficulty concentrating, sleepiness, weakness
	KEPPRA® ( <i>levetiracetam</i> )	1000 mg. - 3000 mg.	Sleepiness, fatigue, poor coordination, loss of strength, dizziness
	KLONOPIN® ( <i>clonazepam</i> )	1.5 mg. – 20 mg.	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes
	LAMICTAL® ( <i>lamotrigine</i> )	100 mg. – 500 mg.	Dizziness, headache, blurred vision, clumsiness, sleepiness, nausea, skin rash
	LYRICA® ( <i>pregabalin</i> )	150 mg. – 600 mg.	Dizziness, blurred vision, weight gain, sleepiness, difficulty concentrating, swelling of hands and feet, dry mouth
	MYSOLINE® ( <i>primidone</i> )	250 mg. – 1000 mg.	Clumsiness, dizziness, appetite loss, fatigue, drowsiness, hyperirritability, insomnia, depression, hyperactivity (children)
	NEURONTIN® ( <i>gabapentin</i> )	900 mg. – 3600 mg.	Sleepiness, dizziness, clumsiness, fatigue, twitching
	PHENOBARBITAL ( <i>phenobarbital</i> )	100 mg.	Drowsiness, irritability, hyperactivity (children), behavioral problems, difficulty concentrating, depression
	PHENYTEK® ( <i>extended phenytoin sodium</i> )	200 mg. – 400 mg.	Clumsiness, insomnia, motor twitching, nausea, rash, gum overgrowth, hairiness, thickening of features
	TEGRETOL® ( <i>carbamazepine</i> )	600 mg. – 1200 mg.	Dizziness, drowsiness, blurred or double vision, nausea, skin rashes, abnormal blood counts (rare)
	TEGRETOL XR® ( <i>extended release carbamazepine</i> )	600 mg. – 1200 mg.	Dizziness, drowsiness, blurred or double vision, nausea, skin rashes, abnormal blood counts (rare)
	TOPAMAX® ( <i>topiramate</i> )	200 mg. – 400 mg.	Confusion, sleepiness, dizziness, clumsiness, difficulty thinking or talking, tingling sensation of the skin, nausea, decreased appetite
	TRANXENE® ( <i>clonazepam</i> )	15 mg. – 45 mg.	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes
	TRILEPTAL® ( <i>oxcarbazepine</i> )	600 mg. – 2400 mg.	Difficulty concentrating, sleepiness, fatigue, dizziness, double vision, nausea, unsteadiness, rash
	ZARONTIN® ( <i>ethosuximide</i> )	500 mg. – 1500 mg.	Appetite loss, nausea, drowsiness, headache, dizziness, fatigue, rash, abnormal blood counts (rare)
	ZONEGRAN® ( <i>zonisamide</i> )	100 mg. – 600 mg.	Sleepiness, dizziness, loss of appetite, headache, nausea, irritability, difficulty concentrating, unsteadiness, fever, kidney stones, rash (should not be used in individuals allergic to sulfa drugs)
	DIASTAT® ACUDIAL™ ( <i>diazepam rectal gel</i> )	Average Single Dose 0.2 mg. – 0.5 mg./kg.	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes

The following medicine is not prescribed for daily, long-term use, but to stop episodes of prolonged or cluster seizures.

Actual doses for a person with epilepsy may be higher or lower than the doses listed.

Not all individuals experience side effects. This partial list names some side effects individuals may experience.



## CALIFORNIA CALENDAR OF EVENTS

### Get involved in state-wide advocacy efforts:

California Neuro-Alliance Public Policy Conference • Legislative Breakfast  
Statewide Forum • Public Policy Institute/Kids Speak Up Speak Out

### Northern California Events:

**JANUARY:**

Employment Law and Epilepsy:  
Know Your Rights

**FEBRUARY:**

Take Charge of the Facts High School  
Training  
School Nurses conference  
Women's Forum

**MARCH:**

Epilepsy Professionals Dinner Program

**APRIL:**

A Day of HOPE Conference

**MAY:**

15th annual Stroll for Epilepsy

**JUNE:**

Epilepsy Professionals Dinner Program  
Camp Coelho

**JULY:**

Epilepsy Conference in Las Vegas

**AUGUST:**

Bynoe Golf Tournament

**SEPTEMBER:**

Epilepsy Professionals Dinner Program

**OCTOBER:**

Sutter Neuroscience Sacramento Conference

Haley's Heroes Golf Tournament

Poker Run

**NOVEMBER:**

Stanford, UCSF, California Pacific  
Living, with Epilepsy Conference  
California Pacific Take Charge of Epilepsy  
Conferences

**DECEMBER:**

Legal Information: Special Needs Trusts and  
Navigating Social Security



### San Diego County Events:

**JANUARY:**

California School Nurse Organization con-  
ference

Disney on Ice Family Outing

**FEBRUARY:**

School Nurse Conference

**MARCH:**

Epilepsy Professionals Dinner Program  
Take Charge of the Facts High School  
Training

**APRIL:**

Sharon's Ride, Run, & Walk

**MAY:**

Epilepsy Parent Seminar

**JUNE:**

Professional Epilepsy Education Conference  
Camp Coelho (teen camp)

**JULY:**

Camp Quest at Camp Marston  
(ages 8-12)

**AUGUST:**

Community Epilepsy Education Conference  
Family outing to the Ball Park

Award Reception for Academic Scholarship  
Winners

**SEPTEMBER:**

Back to School Parents meeting

**OCTOBER:**

Pumpkin Patch Family Fun  
Take Charge of the Facts High School  
Training

**NOVEMBER:**

Gingerbread City Gala

**DECEMBER:**

Gingerbread Kids!



### Greater Los Angeles Events:

**FEBRUARY:**

Epilepsy Decade Dinner & Dance  
California Women & Epilepsy Conference

**MARCH:**

Team Epilepsy in the LA marathon

**JUNE:**

Epilepsy Teen Retreat

**AUGUST:**

Epilepsy Family Picnic

**SEPTEMBER:**

Epilepsy Family Camp

**OCTOBER:**

Epilepsy Freedom Walk

**NOVEMBER:**

Epilepsy Brain Summit

**DECEMBER:**

Winter Retreat for Adults  
Holiday Gingerbread Village  
Family Holiday Party



**EPILEPSY FOUNDATION**  
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