



# Epilepsy and Seizure Disorders:

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A Resource  
Guide  
for Parents

# Notes and Acknowledgements

## Notes to the reader:

- The information contained in this guide is not intended as, and is not a substitute for, professional medical advice. A child's medical team should be consulted about all decisions regarding clinical care and treatment. No pharmaceutical funding was used in the development of this guide.
- Throughout the text, we use the word “child”. Please understand that we use this term to refer to a child of any age between birth and 21 years.
- Resources for which we were able to verify accessibility in languages other than English have the following notation included in the contact information:



= materials in language indicated



= staff conversant in language indicated

## Photograph acknowledgements:

Many of the photographs in the *Guide* were taken at Camp Coelho\* ( June 2007 ) and appear courtesy of the Epilepsy Foundation of Northern California, camp staff, and participating families.

The photograph on page 27 was taken during a Parent Epilepsy Training Videoconference, May 29, 2007, presented by the USC University Center for Excellence in Developmental Disabilities, Childrens Hospital Los Angeles.

\* Camp Coelho, coordinated by the Epilepsy Foundation of Northern California, is a six-day overnight camp offered free of charge to children, ages 9-15, with a primary diagnosis of epilepsy. It is held at Camp Wawona in Yosemite National Park. Camp goals are to provide a safe, enjoyable residential camping experience for children with a primary diagnoses of epilepsy; build self-esteem by promoting self-confidence, competency, and social interaction; and to foster independence in a safe environment away from home. For more information, please contact the Epilepsy Foundation of Northern California (see page 9).

# Table of Contents

Notes and Acknowledgements (inside front cover)	
Introduction	i
Section 1: Understanding Epilepsy/Seizure Disorder	1
What is epilepsy/seizure disorder?	1
What are the different kinds of epilepsy/seizure disorder?	1
How is epilepsy/seizure disorder diagnosed?	3
What causes epilepsy/seizure disorder?	4
What might trigger a seizure?	4
What are the treatment options?	5
Section 2: Health Care for My Child — Access to Care/Access to Services	7
What do I need to know about taking care of my child?	7
What organizations can help me find the help we need?	9
How can I pay for or access the care my child needs?	9
Who are the members of my child's health care team?	14
How can I assure the best health care for my child?	15
Section 3: Advocacy & Support	19
Where can I find support from other parents like me?	19
What do I need to know about my child attending school?	22
How can I educate others about my child's epilepsy/seizure disorder?	24
References	26
Appendix: Forms	27

Dear Parent or Caregiver,

Children are one of life's greatest gifts. As parents, we want to do all we can to nurture and take care of our children. As a parent of a child with epilepsy, also referred to as seizure disorders, you face the additional challenge of learning as much as you can about your child's special needs. This *Guide* was written with you in mind. It was written to give you some very basic information, including an introduction to epilepsy and seizure disorders. It is not intended to provide medical advice. Any questions related to the medical treatment of your child should always be addressed to your child's pediatrician/family physician or neurologist.

While this *Guide* may not provide all of the information you are looking for, it should help you begin your search. Throughout ( this *Guide* ) , we include information about additional resources that we hope will be useful as you begin this journey – a journey that is likely to evolve as you become more knowledgeable about your child's condition. Clearly not every parent needs or seeks the same information, so take from this information what applies and is of value to you and your child.

I would like to extend a warm thanks to the following parents of children with epilepsy who spent many hours reviewing the *Guide* and providing advice on its content: Sandra Bohlin, Tara Dilliplaine, June Ganley, Wendy Longwell, Mara McGrath, Olga Sanchez- Farah. I would also like to recognize the participation of the three California Epilepsy Foundation affiliates in the development and review of the *Guide*, with special thanks to Neva Hirsch Korn, Susan Pietsch-Escueta, and William Stack. The *Guide* would not be possible without the dedicated work of Maureen Maki, USC UCEDD, and Mouna Raad, Parents Helping Parents, Santa Clara, CA, to whom I am very grateful for reviewing existing educational materials, talking with families, and compiling information from myriad sources. Finally, thanks to Laura Schweers, USC UCEDD, Project Coordinator, for her role in editing and print design.

Cary Kreutzer, Project Director  
University of Southern California, University Center for Excellence in  
Developmental Disabilities at Childrens Hospital Los Angeles

# Understanding Epilepsy/ Seizure Disorder

## What is epilepsy/ seizure disorder?\*

The brain contains millions of nerve cells called neurons that communicate electronically and signal to each other. A seizure occurs when there is a sudden and brief excess surge of electrical activity in the brain between nerve cells. This can cause abnormal movements, change in behavior, or loss of consciousness.

Seizures are not a mental health disorder. Instead, epilepsy is a neurological condition that is still not completely understood.

Having a single seizure does not mean that a child has epilepsy. A child has epilepsy when he or she has two or more seizures without a clear cause such as fever, head injury, drug use, alcohol use, or sleep deprivation. About two million Americans have epilepsy. Of the 181,000 new cases that develop each year, up to 50% are children and adolescents. About 300,000 children under the age of 14 in the United States have this condition. It develops in children of all ages and can

affect them in different ways.<sup>1</sup>

## What are the different kinds of epilepsy / seizure disorder?

There are many kinds of epilepsy. They each cause different behaviors and they each need different treatments. Identifying the type (or types) will help your child's doctor suggest treatment options.<sup>2</sup>

### Generalized Seizures

This type of seizure involves the whole brain and is the most common type of epilepsy. In a generalized seizure, the abnormal electrical activity affects the entire brain. These seizures produce muscle twitches, convulsions and loss of consciousness. People with this type of epilepsy do not remember having a seizure.

### Partial Seizures

This type of seizure involves only part of the brain. Sometimes a partial seizure can spread to involve the whole brain.

\* Some people use the term "seizure disorder" instead of "epilepsy" to describe this condition. In fact, both terms mean the same thing – an underlying tendency to experience seizures.

This is known as a partial seizure that secondarily generalizes.

The following chart<sup>3</sup> contains more information about the different types of generalized and partial seizures. Also see page 18 for information about first aid and safety specific to seizure type.



SEIZURE TYPE		DESCRIPTION
GENERALIZED	<b>Tonic-clonic or Grand Mal</b> (loss of consciousness)	This is the most common sort of generalized seizure and is the most recognized epileptic seizure. The person becomes stiff and falls to the ground. Teeth clench and the arms, and usually the legs, begin to jerk rapidly and rhythmically. The seizure usually lasts no more than a few minutes, after which the jerking slows and stops.
	<b>Absence or Petit Mal</b> (loss of consciousness)	During an absence seizure it might seem like the person is daydreaming. However, in an absence seizure the person cannot be alerted or woken up. They are unconscious for a moment and totally unaware of what is happening around them. These seizures usually last a few seconds.
	<b>Myoclonic or Jerks</b> (no loss of consciousness)	Myoclonic means a jerking or twitching of a muscle. During this seizure brief shock-like jerks of a muscle or group of muscles occur. These usually involve the neck, shoulders, and upper arms. Myoclonic jerks occur most frequently in the morning and often occur in clusters. Although the seizures are brief, they can be extremely frustrating, resulting in spilt drinks or similar incidents.
	<b>Tonic and Atonic</b> (loss of consciousness)	Tonic seizures result in all muscles contracting. The body stiffens and the person will fall over if unsupported.  Atonic seizures, in a way, are the opposite of tonic seizures. Instead of the body going stiff, all muscle tone is lost and the person simply drops to the ground. Although the person falls heavily, they are usually able to get up again right away. When the body goes limp it inevitably falls forward causing potential head injuries.
	<b>Status Epilepticus</b> (loss of consciousness)	This seizure is characterized by frequent, long-lasting seizures without regaining consciousness between attacks.
PARTIAL	<b>Simple</b> (no loss of consciousness)	In these types of seizures, even though a person's consciousness is not impaired, it does not mean that the person experiencing this type of seizure is able to stop or control the seizure. Simple partial seizures can be different depending on where in the brain the epileptic activity is occurring. Examples of symptoms are the movement of a limb, tingling, experiencing a smell or taste, and going pale or sweating.
	<b>Complex</b> (loss of consciousness)	Because a person's consciousness is impaired in this type of seizure, the person will not remember the seizure or their memory of it will be distorted. Others may believe the person is fully aware of what they are doing, but they are not. Usually the person loses awareness and stares blankly. Most people move their mouth, pick at the air or their clothing, or repeat other purposeless actions. These movements are called "automatisms". They usually last between 30 seconds and 2 minutes.

## How is epilepsy/ seizure disorder diagnosed?

Your doctor will ask a lot of questions when trying to diagnose epilepsy and determine the type(s). The diagnosis is based on sev-

eral exams and tests in addition to an interview about your child's condition. The facts you provide the doctor are very important in diagnosing your child's epilepsy and deciding on treatment.

The following chart<sup>4</sup> outlines some of the tools a doctor uses for diagnosis.

TOOLS FOR DIAGNOSIS		
INTERVIEW	<b>Information about Seizure(s)</b> The doctor will ask for a complete description of what happened.	Questions that may be asked: <ul style="list-style-type: none"> <li>• What circumstances surrounded the seizure?</li> <li>• What seemed to bring on the seizure?</li> <li>• What happened before the seizure?</li> <li>• How did your child feel before, during, and after the seizure?</li> <li>• Description of seizure behavior?</li> <li>• What happened after the seizure?</li> <li>• Where was the child when the seizure occurred?</li> </ul>
	<b>Medical History</b>	You may be asked about: <ul style="list-style-type: none"> <li>• family history of seizures</li> <li>• medical conditions or medications</li> <li>• general medical history of your child</li> </ul>
PHYSICAL EXAM	An examination of muscle strength, reflexes, eyesight, hearing and ability to detect various sensations, are tested to better understand the cause of the seizures.	
NEUROLOGICAL EXAM ( TESTS )	<b>EEG</b> ( <i>electroencephalogram</i> )	An EEG measures the electrical impulses in the brain. During an EEG, electrodes (small metal disks) are attached to specific locations on the head and monitored. Abnormal electrical spikes indicate seizure activity.
	<b>CT or CAT Scan</b> ( <i>computerized axial tomography</i> )	A CT scan is an x-ray of the brain that creates three-dimensional images of the brain and shows possible abnormalities.
	<b>MRI</b> ( <i>magnetic resonance imaging</i> )	An MRI is another imaging method using magnets instead of X-rays. MRI tests provide detailed images of the brain. CT or MRI scans may be used to search for any growths, scars, or other physical conditions in the brain that may be causing the seizures.
	<b>Blood Tests</b>	Tests to measure white blood cell count, blood sugar, sodium, calcium and electrolyte levels, and liver and kidney function. Blood tests also help rule out other illnesses.
	<b>Other Tests</b>	Other tests may be ordered as needed.

## What causes epilepsy/ seizure disorder?

Many parents wonder if they have somehow caused their child's epilepsy. They search for a way to understand why this is happening to their child. But it is unlikely that a parent or anyone did anything to cause the epilepsy.

Finding the cause of epilepsy is difficult. For seven out of ten children with epilepsy, there is no known cause. These children are said to have idiopathic epilepsy. "Idiopathic" means "of unknown cause."

However, there are many known causes. Understanding and identifying the causes help to diagnose the type(s) of epilepsy. Possible causes include the following:

- problems with brain development before birth
- lack of oxygen during or following birth
- a serious head injury that leaves a scar in the brain



- unusual structures in the brain
- tumors
- a prolonged seizure with fever
- the after-effects of severe brain infections, such as meningitis or encephalitis
- genetic factors<sup>5,6</sup>

## What might trigger a seizure?

Some people report very specific triggers or immediate causes that can bring about a seizure. Children with epilepsy are more likely to have a seizure (have a lower seizure threshold) when they have a cold, the flu, or other common illnesses. Some common seizure triggers include the following:

- not enough sleep
- food allergies
- stress
- flashing lights (e.g., from video games, strobe lights)
- alcohol
- illicit drugs
- dehydration

## What are the treatment options?

Childhood epilepsy is usually treated with medications that prevent seizures. If the medications do not work or if the child has too many side effects, there are other treatment options. These include surgery, the ketogenic diet, or vagus nerve stimulation (VNS).

### Medication

Children often take the same antiepileptic medications as adults. Medication may be in the form of tablets, sprinkles, capsules or syrup.

These medications are designed to prevent seizures. Some are successful with a few seizure types; others have a broader range of action. Whenever possible, doctors try to control seizures with one medication. Some children, however, may need to take more than one.

Children may respond so well to medication that no further seizures occur as long as the medication is taken regularly as directed by the doctor. Not having seizures does not mean that the medication is no longer needed. Always ask the doctor before stopping a seizure medication. Doing so without medical supervision may result in a seizure or another type of reaction.

There are recent concerns regarding differences between brand and generic

medications. For more information about these concerns, medications, and medication side effects, contact your doctor or the Epilepsy Foundation at 800-332-1000.

#### MEDICATION TIPS:

- Make sure that you understand the dosages of medicine prescribed by your doctor such as the number of pills or teaspoons required for each dose as well as the number of doses and times (e.g., morning, noon, night) to administer each dose. Also, make sure that you understand the best method for administering each medication (e.g., by dropper, mixed with food or liquid, or crushed).
- Ask your doctor or pharmacist about possible side effects associated with each medication your child is taking and what you should do if they occur.
- Keep follow-up appointments. Some medications require periodic blood tests that are important to your child's health. Ask the doctor at the end of each visit when he or she wants to see you both again, and schedule the next appointment.
- Don't change the dose or stop giving seizure medication on your own without first talking with your child's doctor.
- Ask for refills from your pharmacy several days before the medication is due to run out.
- Ask your doctor or pharmacist about over-the-counter medications as they may interfere with the epilepsy medication your child is taking. Also, check with the pharmacist when filling other prescriptions for your child.
- Ask your doctor how to handle fever associated with childhood illness. Ask, too, about the best way to give medication when a child has a stomach virus and cannot keep medication down.
- Find out what you should do if your child misses a dose. Ask whether the dosing schedule is flexible and what to do if your child is scheduled for a dose when he/she is sleeping.

## Ketogenic Diet

If medications do not control a child's seizures, a doctor may recommend a special high fat, low carbohydrate diet called a ketogenic diet.

Carbohydrates are strictly limited and parents have to be very careful that the child does not eat foods that are not on the diet or have not been pre-measured and pre-weighed.

The diet requires a team effort – the family, the physician, the dietitian, the nurse, and, if the child is old enough, the child himself/herself – all working together to make sure the diet is followed and any side effects are monitored.

### WARNING:

The ketogenic diet is not a do-it-yourself diet. It must be monitored by a medical team.



## Vagus Nerve Stimulation

Vagus nerve stimulation (VNS) is a type of surgical intervention that may be tried



when seizures cannot be controlled by other methods.

The treatment works by sending regular small bursts of electrical energy to the vagus nerve, a large nerve in the neck that leads directly into the brain.

The energy comes from a small disk-like generator, about the size of a stop watch, surgically implanted under the skin on the chest.

The generator is connected to wires under the skin that are wrapped around the vagus nerve. The VNS is put under the skin by a surgeon.

## Specialized Care

Specialized care for children with difficult (refractory) epilepsy is available at special centers around the country. Many offer in-depth evaluations, surgery, the ketogenic diet, and VNS therapy. For information about sources of specialized care near you, call the National Association of Epilepsy Centers or any other organization listed on page 14.

# Health Care for My Child

## Access to Care / Access to Services

### What do I need to know about taking care of my child?

The most important way to help your child and his or her physicians is to be an active member of your child's health team. This means being prepared for visits, keeping records, learning to ask questions and advocating for your child. Networking with other parents of children with epilepsy may become a source of information, strength, and inspiration as you learn to live with your child's epilepsy. And most of all, do not forget to take care of yourself – without you, your child's number one advocate is gone.

### Make observations

It can be very frightening to see your child having what appears to be a seizure. However, it is important to remain as calm as possible so you can describe exactly what happened to the doctor. It is unlikely that your doctor will ever see your child have a seizure. Your observations and knowledge of your child are vital in helping the doctor reach a diagnosis. It is a good idea to write down these and all observations about the seizure or subsequent behavior so that you can tell your doctor exactly what hap-

pened. Two examples of forms to help you track this information are included in the Appendix section of this *Guide* (*Seizure Log* [F1] and *Seizure Description Sheet* [F2]). If possible, try to record a video of your child during a seizure so that your child's doctor can observe exactly what happens and what steps you take in response. Make sure that you or someone is still tending to your child and the seizure during the taping, keeping your child's health and safety a priority at all times.

### Educate yourself – ask questions

It is perfectly normal to feel overwhelmed and confused when first learning about epilepsy. But if you ask lots of questions and gather as much information as you can, you are choosing the most effective way to help your child. Learning as much as you can about epilepsy will build your self-confidence and improve your ability to respond to your child's needs. In this *Guide* you will encounter many internet resources, as well as physical addresses and phone contact information. If you do not have a computer with internet access at home or work, you can go to your local library and use one of their public computers to look up the links for free.

You must be your child's advocate. Ask for what you want from doctors. Put everything in writing. You may find friends and advocates at the school district, the doctor's office, or at an Early Intervention program that can help you. If you are not satisfied with the services you receive from your health plan, medical group, or provider, talk to them about your concerns. If you are still not satisfied, document your concerns in writing. Sample letters can be obtained from your family resource center or online ([www.hrh.org](http://www.hrh.org) – click on *Consumer Action Guides*).

There is a wealth of information available about epilepsy in children. There are organizations on the national, state, and local level that can direct you about who to call and where to look for the information you need. There are books, brochures, websites, training classes, and more to help you find your way and learn about your child and his or her condition.<sup>7</sup>

## Get organized

One of the most important things you can do for yourself and your child is to organize information you are receiving. It is very helpful if you have complete medical records available for all the doctors who are treating your child.<sup>8</sup>

## Attend support groups and networks with other parents

Find support groups for yourself, your spouse, and your family. Take care of

yourself to avoid being overwhelmed or getting sick. Your children may sense your stress and it can scare them. You need a place to talk about your fears and concerns. Ask your nearest epilepsy organization about where groups in your area are meeting. Your doctor, nurse, Early Intervention coordinator, or your local hospital may also be able to tell you what associations exist and where support groups may be available. If you go online to a chat room, be sure that there is a medical moderator in the chat room.

## Take care of yourself

As parents, our needs always seem to come last. But we can not continue as effective caregivers if we do not take time to care for ourselves. Giving all that we can to our loved ones requires taking care of ourselves first. Here are some basic tips<sup>9</sup>:

- Schedule time for yourself each week— take a walk, read a book, take a yoga class, indulge in a makeover, or even go shopping. Take the time to do something that makes you happy.
- Stay in touch with yourself. Keep a journal in which you can express feelings and thoughts.
- Stay in touch with friends.
- Try to eat healthfully and stay physically active to prevent chronic disease.
- Look your best. Although it takes energy, it also boosts your spirit.
- Accept help – extra hands at doctors' appointments, grocery shopping, child care, car pool, etc...

Also, parents may benefit from mental health counseling services and are encouraged to bring up their mental health concerns ( e.g., depression, anxiety ) to their primary health care provider.

#### TIPS FOR CAREGIVERS:

The following website has some great tips:



[www.americanheart.org/presenter.jhtml?identifier=3039889](http://www.americanheart.org/presenter.jhtml?identifier=3039889)

## What organizations can help me find the help we need?

The following organizations can help direct you to information and services in your area.


### Epilepsy Foundation

8301 Professional Place East  
Landover MD 20785-2238  
800-332-1000  
[www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

Spanish:  



### Epilepsy Foundation of Northern California

5700 Stoneridge Mall Rd., Suite 295  
Pleasanton, CA 94588  
800-632-3532  
E-mail: [efnca@epilepsynorcal.org](mailto:efnca@epilepsynorcal.org)  
[www.epilepsynorcal.org](http://www.epilepsynorcal.org)

Spanish:  



### Epilepsy Foundation of Greater Los Angeles

5777 West Century Blvd, Suite 820  
Los Angeles, CA 90045  
800-564-0445  
E-mail: [SOS@epilepsy-socalif.org](mailto:SOS@epilepsy-socalif.org)  
[www.epilepsy-socalif.org](http://www.epilepsy-socalif.org)

Spanish:  



### Epilepsy Alliance of Orange County

1500 Adams Ave., Suite 314  
Costa Mesa, CA 92626  
714-557-0202  
E-mail: [janna@epilepsyalliance.org](mailto:janna@epilepsyalliance.org)  
[www.epilepsyalliance.org](http://www.epilepsyalliance.org)

Spanish:  

### Epilepsy Foundation of San Diego County

2055 El Cajon Boulevard  
San Diego, CA 92104  
619-296-0161  
E-mail: [info@epilepsysandiego.org](mailto:info@epilepsysandiego.org)  
[www.epilepsysandiego.org](http://www.epilepsysandiego.org)

Spanish:  

### National Association of Epilepsy Centers

5775 Wayzata Blvd., Suite 200  
Minneapolis, MN 55416  
888-525-6232  
E-mail: [info@naec-epilepsy.org](mailto:info@naec-epilepsy.org)  
[www.naec-epilepsy.org/](http://www.naec-epilepsy.org/)

Spanish/French:  

## How can I pay for or access the care my child needs?

There are services in place to help you find and pay for you child's health care. Private and public programs provide access to services and payment options for those services. Trying to find your way through all the information can be overwhelming to anyone. Someone from one of the organizations listed in the previous section should be able to help.

Local epilepsy organizations may be able to provide the names of doctors who accept private insurance, Medicaid, Medicare, CCS, Healthy Families, or

Healthy Kids, or doctors who are willing to see patients at reduced rates. They may also know of clinics where care is given free of charge. Online resources offer easy ways to search for doctors as well.

Here are some of the important programs and service delivery systems (e.g., Managed Care) you will come across as you go about getting care for your child.

## Managed Care

Managed Care is a common way that services are delivered under medical insurance plans or Medi-Cal/Medicare. Managed Care links coverage with health care providers in its network. If you have health care coverage through this type of plan, you are an enrollee or subscriber. Enrollees receive their health care from a group of approved doctors and hospitals, called a provider network.

Often enrollees in a managed care plan are assigned to a primary care doctor, or gatekeeper. The gatekeeper's job is to see that the enrollee receives routine medical care such as regular check-ups. The gatekeeper is also the one who decides if the enrollee needs to see a specialist - a doctor or other health care provider who has special training in a particular condition.

There two basic types of managed care plans are Health Maintenance Organizations (HMOs) and Preferred Provider Organizations (PPOs). The main difference between these two plans is that HMOs require their enrollees to receive all of their care from

within the plan's network, while PPOs give enrollees the option of using providers either within or outside the plan's network of providers.

Another type of managed care called Exclusive Provider Organization (EPO) is very similar to an HMO. In simple terms, an EPO is a much smaller PPO, offering a very limited number of providers, who offer deeper discounts on their rates because they see a higher volume of patients.

## CCS (California Children's Services)

CCS is a program that pays for specialty health care services for eligible children/young adults with serious and/or chronic medical conditions. There is a CCS program in every county in California.

The program is open to children/young adults who meet all of the following requirements:

- Is less than 21 years of age
- Has a CCS medically eligible condition. Not every child/young adult with epilepsy will be eligible for CCS services. He/she must be evaluated by CCS to determine eligibility.
- Meets the residential requirements
- Is enrolled in Medi-Cal or Healthy Families programs or has an annual family income of less than \$40,000 or is projected to spend over 20% of annual family income on treatment of the CCS condition.

If you think your child might be eligible, call your local CCS office to determine if he/

she meets CCS eligibility requirements. To find addresses and phone/fax numbers for CCS offices, go to the website listed below. Links to most county health department websites are also provided.

#### **CCS Directory**

[www.dhcs.ca.gov/services/ccs/Pages/countyoffices.aspx](http://www.dhcs.ca.gov/services/ccs/Pages/countyoffices.aspx)

## Mental Health Services for Children

Mental health refers to the successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and cope with adversity.

Children may require the services of a mental health provider for a variety of reasons; their needs may be related to stresses in the home, family, or school or they may be related to stress or an emotional disturbance associated with special needs and/or learning disabilities. Mental health services are available for children through several different programs. Children who have special health care needs may be eligible to receive services through more than one program, therefore coordination of care is important. The Department of Mental Health (DMH) offers programs to support children enrolled in Medi-Cal and Healthy Families and adults with mental health conditions. In addition, CCS may provide funding for mental health issues related to the CCS eligible condition. Finally, commercial insurance may also include a mental health benefit. Information about this can be ob-

tained from your member services department (check your health insurance card for the number).

For a listing of CA County Mental Health Departments, go to the following website:

#### **California DMH Listings by County**

[www.dmh.ca.gov/docs/CMHDA.pdf](http://www.dmh.ca.gov/docs/CMHDA.pdf)

## Regional Centers

The Regional Center system in California is an entitlement program designed to serve individuals with developmental disabilities regardless of income and to assist their families. Regional Centers serve all ages, from newborns to seniors. There are 21 Regional Centers in the state.

Developmental disabilities, for purposes of Regional Center eligibility, include mental retardation, cerebral palsy, epilepsy, autism and other handicapping conditions related to mental retardation or requiring treatment similar to that required for developmentally delayed individuals. The disability must begin before the person is 18 years old, must continue, or be likely to continue, indefinitely, and must constitute a substantial handicap for the individual. Developmental disabilities do not include handicapping conditions that are solely physical, psychiatric, or related to learning disabilities. To locate a Regional Center serving your area, go to the website listed below.

#### **Regional Center Directory**

[www.dds.ca.gov/rc/rclist.cfm](http://www.dds.ca.gov/rc/rclist.cfm)

## Medi-Cal & Healthy Families



California's Medicaid program (Medi-Cal) provides health insurance to low-income families and individuals who lack health insurance. The most commonly used forms of Medi-Cal are:

1. Fee-for-service Medi-Cal
2. Medi-Cal managed care
3. Share of cost Medi-Cal
4. Medi-Cal waiver services

For those families who do not have health insurance and make too much money to qualify for Medi-Cal, Healthy Families provides low cost health insurance. Healthy Families offers different plans from which to choose, and includes health, dental and vision care. Small copayments may be charged for visits.

### Medi-Cal Information & Healthy Families

888-747-1222 or  
877-KIDS-NOW (877-543-7669)  
[www.medi-cal.gov](http://www.medi-cal.gov)

Spanish:  

Medi-Cal policy institute:  
[www.medi-cal.org](http://www.medi-cal.org)


## Medication Assistance Programs

The following organizations offer prescription drug assistance:

### Free Medicine Program

Established by volunteers, the Free Medicine Program helps patients substantially reduce or completely eliminate their prescription drug costs.

800-921-0072  
[www.freemedicineprogram.com](http://www.freemedicineprogram.com)



Spanish:  (main desk only—7am to 1pm, M-F)

### Partnership for Prescription Assistance

A partnership bringing together America's pharmaceutical companies, doctors, other health care providers, patient advocacy organizations, and community groups to help qualifying patients who lack prescription coverage get the medications they need through the public or private program that is right for them.

888-477-2669

[www.pparx.org](http://www.pparx.org)

Spanish:  

### Rx Assist

A nonprofit group that provides information to health care providers to help patients get medications.



[www.rxassist.org](http://www.rxassist.org)

### Rx Help for Californians

A website designed to help low-income, uninsured California residents get free or discounted brand-name medications.

877-777-7815

[www.rxhelpforca.org](http://www.rxhelpforca.org)

Spanish:  

### Rx Hope

A patient assistance company partially funded by the pharmaceutical manufacturers. It promises to speed requests for no-cost medications. The website includes information about medications covered by assistance programs.

800-511-2120



[www.rxhope.com](http://www.rxhope.com)

### Together RX Access

A free prescription savings program for eligible individuals/families who lack prescription drug coverage and are not eligible for Medicare.

800-444-4106


[www.togetherrxaccess.com](http://www.togetherrxaccess.com)

Spanish:  

Pharmaceutical manufacturers also provide assistance with prescription drugs for low-income families. Try contacting the specific manufacturers for details:

**Abbott Laboratories** ( *Depakote* )

800-222-6885


[www.helpingpatients.org](http://www.helpingpatients.org)Spanish: **Cephalon, Inc** ( *Gabitril* )

866-209-7589

Spanish: Interpreter available

**Eisai** ( *Zonegran* )


866-694-2550

Spanish: **GlaxoSmithKline** ( *Lamictal* )


888-825-5249

[www.bridgestoaccess.com](http://www.bridgestoaccess.com)Spanish:  **Novartis** ( *Tegretol, Trileptal* )



800-277-2254

[www.pharma.us.novartis.com/novartis/pap/pap.jsp](http://www.pharma.us.novartis.com/novartis/pap/pap.jsp)Spanish: **Ortho-McNeil** ( *Topamax* )


877-937-9682 / 800-652-6227

[www.access2wellness.com/a2w/patient-pap.html](http://www.access2wellness.com/a2w/patient-pap.html)Spanish: **Pfizer** ( *Dilantin, Neurontin, Zarontin* )


866-776-3700

[www.pfizerhelpfulanswers.com](http://www.pfizerhelpfulanswers.com)Spanish:  **UCB Pharma** ( *Keppra* )

800-477-7877

Spanish: **Valeant** ( *Diastat, Mysoline* )

800-511-2120

Spanish: 

For a chart of pharmaceutical companies offering assistance programs for epilepsy medications, see *Epilepsy: Patient and Family Guide*, 2nd edition, pages 135-138, by Orrin Devinsky, MD, F.A. Davis Company, 2002.<sup>10</sup>

## What is HIPAA?

The Health Insurance Portability and Accountability Act (HIPAA) provides rights and protections for participants and beneficiaries in group health plans. HIPAA includes protections for coverage under group health plans that limit exclusions for preexisting conditions; prohibit discrimination against employees and dependents based on their health status; and allow a special opportunity to enroll in a new plan to individuals in certain circumstances. HIPAA may also give you a right to purchase individual coverage if you have no group health plan coverage available and have exhausted COBRA or other continuation coverage.<sup>11</sup>

The law also gives you rights over your health information. Providers and health insurers who are required to follow this law must comply with your right to the following:



- view /get a copy of your health records
- have corrections added to your health information
- receive a notice telling you how your health information may be used and shared
- decide if you want to give permission before your health information can be used or shared for certain purposes.<sup>12</sup>

If you believe your rights are being denied or your health information is not being protected you can do the following:

- file a complaint with your provider or health insurer
- file a complaint with the US government

### HIPAA Information

800-368-1019

[www.hhs.gov/ocr/hipaa](http://www.hhs.gov/ocr/hipaa)Spanish:  

## Who are the members of my child's health care team?

### Possible members<sup>13</sup>

TEAM MEMBER	DESCRIPTION
pediatrician	This is a doctor who specializes in the care and treatment of children and is usually the first to see your child for evaluation. This person may also be referred to as your child's primary care provider. This doctor may run some tests and if he or she suspects seizures will probably refer your child to a neurologist.
neurologist	This is a doctor with special training in disorders of the brain, including epilepsy, and other parts of the nervous system.
pediatric neurologist	This is a neurologist who specializes in children.
epileptologist	This is a neurologist with specialty training in epilepsy who spends most of their time treating people with this disorder. For routine treatment of epilepsy, it is usually not necessary to see an epileptologist. However, for a child with a seizure disorder that is difficult to treat (refractory), an epileptologist may provide an added level of comfort. If possible, an initial consultation with an epileptologist is advantageous and encouraged in new onset epilepsy. Also, consultation may be beneficial in other circumstances, such as counseling about pregnancy and childbirth.
neuro-psychologist	This is a psychologist with training in the neurobiological causes of brain disorders.
pediatric nurse	This is a health care provider educated and trained to care for children who are sick or disabled
pediatric epilepsy nurse	This is a nurse with extra training in pediatrics and neurology.
nurse practitioner	This is a registered nurse who has completed advanced training in the diagnosis and management of common medical conditions.

The organizations and websites listed below offer services to assist you in finding physicians with expertise in epilepsy.

#### Epilepsy Foundation

8301 Professional Place, East  
800-332-1000

[www.epilepsyfoundation.org/drsearch.com](http://www.epilepsyfoundation.org/drsearch.com)

*Use this web address to go directly to the page that offers an online search for doctors near you.*

Spanish:  

#### American Epilepsy Society (AES)

342 N. Main St.  
West Hartford, CT 06111-2507  
860-586-7505

[www.aesnet.org](http://www.aesnet.org)

*The AES website features a searchable member directory where you can find epilepsy specialists near you.*

#### National Association of Epilepsy Centers (NAEC)

5775 Wayzata Blvd., Suite 200  
Minneapolis, MN 55416  
888-525-6232

[www.naec-epilepsy.org](http://www.naec-epilepsy.org)

*The NAEC is a non-profit trade association whose members include more than 60 specialized epilepsy centers.*



## How can I assure the best health care for my child?

### Coordination of care

As more health care professionals are included in your child's health care you may feel overwhelmed and confused. Health care professionals have recognized the need to partner with families in caring for children (see *Characteristics of a Medical Home* below), especially those with special health care needs. For children with epilepsy and their families, such care is therefore ideally provided in a way that feels like a "home". It is sometimes referred to as a "medical home," which is not a building, house, or hospital, but a team approach to providing health care. Your child's primary care doctor or neurologist may assume the role of the "medical home" by taking the lead in coordinating services and helping you to feel connected and supported. The "medical home" is generally the health care provider who best knows your child.

Your role in this partnership is to share your thoughts and concerns, and to be prepared to discuss them, as well as potential solutions, with your child's primary doctor. You will want to ask about your child's medical health care plan (health insurance), medications, referrals, tests and procedures. Other concerns or issues you may want to discuss

with your primary care provider may include recreational activities, school concerns, interactions with siblings, and alternative therapies. Your child's primary care provider should work closely with you and individuals who provide care to your child to assure that all services and supports are coordinated.

#### CHARACTERISTICS OF A MEDICAL HOME<sup>1 4</sup>

- A partnership between your family and your child's primary care clinician
- A relationship based on mutual trust and respect
- Connections to supports and services to meet your child's and family's needs
- Respect for your family's cultural and religious beliefs
- After hours and weekend access to medical consultation about your child
- Families who feel supported in caring for their child
- Your primary care clinician working with your team of other care providers

### Knowing what to do when a seizure occurs

An important way to assure your child's safety is to know what to do when a seizure occurs. Then you can make others aware of the necessary first aid in case your child has a seizure when they are around.

Most seizures are over so quickly that you do not really have much time to do anything. After it is over, you simply make sure that your child was not injured. Tonic-clonic seizures are the most

dramatic and frightening of the seizures, and they usually last longer than other seizures.

Take a look at the table below to review some basic information that should be considered when responding to a child's seizure.



### SEIZURE RESPONSE:

<p><b>WHAT TO DO DURING A SEIZURE</b></p>	<ul style="list-style-type: none"> <li>• Stay calm; most seizures only last a few minutes.</li> <li>• Move things out of the way so your child will not injure himself/herself.</li> <li>• Lay him/her on one side.</li> <li>• Make your child as comfortable as possible — loosen any tight clothing around the neck and put a pillow or something soft under the head.</li> <li>• Pay attention to the length of the seizure.</li> <li>• Keep onlookers away.</li> <li>• Be sensitive and supportive, and ask others to do the same.</li> </ul>
<p><b>WHAT NOT TO DO DURING A SEIZURE</b></p>	<ul style="list-style-type: none"> <li>• Do not put anything in the mouth. While your child may bite his or her tongue during a seizure, trying to put something in the mouth probably will not work to prevent this. You may also get bitten, or you may break some of your child's teeth.</li> <li>• Do not try to hold your child down. People, even children, have remarkable muscular strength during seizures. Trying to pin a child with a seizure to the ground is not easy and restraint can lead to more serious medical complications.</li> <li>• Do not give mouth-to-mouth resuscitation until the seizure is over. After the seizure has ended, give mouth-to-mouth resuscitation only if your child is not breathing.</li> </ul>
<p><b>WHEN TO CALL 911</b></p>	<p>Most seizures are not medical emergencies, but an ambulance should be called if:</p> <ul style="list-style-type: none"> <li>• The seizure lasts longer than 5 minutes or one seizure immediately follows another.</li> <li>• Your child does not resume normal breathing after the seizure ends</li> <li>• Your child was seriously injured during the seizure.</li> <li>• Your child/adolescent is pregnant or has diabetes.</li> <li>• The seizure happens in water, and therefore your child may have inhaled water.</li> <li>• Do not call an ambulance during a typical seizure. For a lot of people, the first response to seeing a seizure is to call 911. But for the vast majority of seizures, that is not necessary. It is also frightening for a child to spend an afternoon in the hospital unnecessarily.</li> </ul>
<p><b>WHAT TO LOOK FOR AFTER A SEIZURE</b></p>	<p>The period immediately after a seizure varies depending on the type, duration, and intensity of the seizure as well as other factors. Some children may feel discomfort from muscle soreness, headache, and pain in the tongue or cheek if those areas were bitten. Your child may feel confused or tired, and his/her skin may appear pale or bluish. For some, the symptoms after a seizure may be more troublesome than the seizure itself. Antiepileptic medications may not alter the seizures, but may minimize those symptoms.</p>



## How can I make sure others are aware of what to do?

Remember to tell others about the appropriate first aid for your child. Use the *Seizure Action Plan* ( form F3 in the Appendix section of this *Guide* ) and customize it to fit your child's needs or create your own “what to do” form. Step by step directions should be numbered and should include comforting steps for your child as well as who to call after a seizure. If possible, involve your child in writing these instructions. Hand this form out to babysitters, school personnel, and anyone else who may be taking care of your child. It is important that they be informed about how to handle a seizure and what to do afterwards. Be sure to include how to reach you as well as the telephone number of your child's doctor.

Please refer to the chart on page 18 for information specific to different seizure types and recommended first aid for each.

### WATER SAFETY:

It is very important to NEVER leave your child alone in the bathtub or in the pool even for a couple of seconds. This is true for all children, but is especially important for children with epilepsy, as seizure occurrences are not predictable.



<b>FIRST AID FOR SEIZURES</b> <sup>15, 16</sup>		
<b>Seizure Type</b>	<b>What to Do</b>	
<b>GENERALIZED</b>	<b>Tonic-Clonic or Grand Mal</b> (loss of consciousness)	<ul style="list-style-type: none"> <li>• Move child away from hard, sharp, or hot objects. Put something soft under child's head. Turn child on one side to keep airway clear.</li> <li>• Do not put anything in child's mouth or give liquids or medications during or immediately after the seizure.</li> <li>• Do not try to hold the child's tongue; it cannot be swallowed.</li> <li>• Do not restrain movement.</li> <li>• Cushion the head, remove glasses and any tight neckwear, and turn child on side. Do not restrain movements unless they place the child in danger. Do not put anything in the mouth. If the seizure lasts more than two minutes or if it is the first time that child has had a seizure, you should get medical help immediately.</li> <li>• Reassure the child when consciousness returns.</li> <li>• Usually it is not necessary to call an ambulance if it is known that the child has epilepsy, and the seizure ends after a minute or two.</li> <li>• Call for emergency aid if this is the child's first seizure of unknown cause, if multiple seizures occur, if the seizure lasts longer than five minutes, or if the child seems sick, injured, or unresponsive.</li> </ul>
	<b>Absence or Petit Mal</b> (loss of consciousness)	<ul style="list-style-type: none"> <li>• Observe the child carefully.</li> <li>• Reassure the child if he or she is frightened or confused.</li> <li>• Try to count and record episodes.</li> <li>• No first aid is necessary, but if this is the first observation of an absence seizure, medical evaluation is recommended.</li> </ul>
	<b>Myoclonic or Jerks</b> (no loss of consciousness)	<ul style="list-style-type: none"> <li>• Speak calmly to the child and other children around him or her.</li> <li>• If the child is walking, guide him or her gently to a safe place.</li> <li>• Stay close until the seizure has ended and the child is completely aware of where he or she is and can respond normally when spoken to.</li> <li>• If the seizure is a first occurrence, a medical check-up is recommended.</li> <li>• First aid is usually not needed. However, a child having a myoclonic seizure for the first time should receive a thorough medical evaluation.</li> </ul>
	<b>Tonic and Atonic or Akinetic</b> (loss of consciousness)	<ul style="list-style-type: none"> <li>• Comfort the child and check to see if he or she is hurt. A medical check-up is recommended.</li> <li>• No first aid is needed (unless there is injury from a fall), but if this is a first tonic or atonic seizure, the child should be given a thorough medical evaluation.</li> </ul>
	<b>Status Epilepticus</b> (loss of consciousness)	<ul style="list-style-type: none"> <li>• This condition requires immediate medical attention. Call for medical help.</li> <li>• Do not attempt to transport an actively seizing child in your car unless an ambulance is not available.</li> <li>• If the child has had this type of seizure before, follow advice specifically given by the child's doctor.</li> </ul>
<b>PARTIAL</b>	<b>Simple</b> (no loss of consciousness)	<ul style="list-style-type: none"> <li>• No first aid necessary, but if this is the first observation of the seizure, medical evaluation is recommended.</li> </ul>
	<b>Complex</b> (loss of consciousness)	<ul style="list-style-type: none"> <li>• Speak calmly to the child and other children around him or her.</li> <li>• If the child is walking, guide him or her gently to a safe place.</li> <li>• Stay close until the seizure has ended and the child is completely aware of where he or she is and can respond normally when spoken to.</li> <li>• Pay attention to the duration of the seizure; most partial seizures last a minute or two. However, a child may be confused for up to half an hour afterwards. Longer periods of confusion may mean that seizure activity is continuing and the child needs medical attention.</li> </ul>

# Advocacy and Support

## Where can I find support from other parents like me?

Support groups may be in person, chat rooms (an area on the internet where you can chat with other members), electronic mailing lists (users can subscribe to a mailing list by sending an e-mail note to a mailing list they learn about), or message boards (an application that allows users to post and reply to messages from other users and review the flow of a discussion – also known as a discussion group). Groups can be used to share valuable information about doctors, medications and treatments. The information, experiences and successes gained through each family's journey can be shared to help other families in similar situations.

Always remember that support groups and online groups are made up of other parents like you. Do not take medical advice from an untrustworthy source and always check with your doctor before trying something new.

### In person support

You can find face-to-face support groups and information about counseling for parents by calling your nearest Epilepsy Foundation affiliate or the National Epi-

lepsy Foundation (see page 9) for contact information). You may also want to contact one (or more) of California's Centers designed to help parents. There are three categories:

#### 1 ) California Family Resource Centers ( FRCs ):

- are part of the state Early Start Program which promotes access to early intervention services for children birth to age three who have, or are at risk for developmental delay,
- are staffed by families of children with special needs,
- offer parent-to-parent support, outreach and awareness,
- offer support for transition out of Early Start,
- help parents, families, and children locate and use needed services,
- offer support services, and resources in many languages, which may include newsletters, resource libraries, websites, sibling support groups, warmlines, and information and referral for parents and professionals.

Some FRCs have additional funding that allows them to provide services to a broader population such as older children and youth. To locate an FRC near

you, go to the website listed below or call the Family Resource Center Network of California ( FRCNCA ) .

#### **FRC Directory**

[www.frcnca.org/directory.html](http://www.frcnca.org/directory.html)

#### **FRCNCA**

5775 Wayzata Blvd., Suite 200

c/o Support for Families



2601 Mission Street, Suite 606

San Francisco, CA 94110

415-282-7494

email: [info@frcnca.org](mailto:info@frcnca.org)

[www.frcnca.org](http://www.frcnca.org)

Spanish:  



## **2 ) California Parent Training and Information Centers ( PTICs ) and Community Parent Resource Centers ( CPRCs ) :**

Parent Training and Information Centers and Community Parent Resource Centers in each state provide training and information to parents of infants, toddlers, children, and youth with disabilities, and to professionals who work with children. This assistance helps parents participate more effectively with professionals in meeting the educational needs of children and youth with disabilities. The PTICs and CPRCs work to improve educational outcomes for children and

youth with all disabilities ( emotional, learning, mental, and physical ) .

#### **PTIC Directory**

[www.taalliance.org/centers/region6.htm](http://www.taalliance.org/centers/region6.htm)

## **3 ) California Family Empowerment Centers ( FECs ) :**

The purpose of the California Association of Family Empowerment Centers is to provide information, resources, technical assistance, and systems change advocacy for a statewide network of local FECs who provide family education, empowerment, and parent-professional collaborative activities for families of children with disabilities ages 3-22 years old.

#### **FEC Directory**

[www.cafec.org/fecmap.htm](http://www.cafec.org/fecmap.htm)

As you are looking for specific answers, training, and support, it is important to realize some of the agencies listed above will only provide you with part of the answer you need. Others may be able to give you a more complete answer. In some cases the Parent Resource Center is also funded as a Parent Training and Information Center and as a Family Empowerment Center. Such centers include Parents Helping Parents in Santa Clara, Matrix Parent Network & Resource Center in Novato, Support for Families in San Francisco, Exceptional Parents Unlimited in Fresno, and Rowell Family Empowerment Center in Redding.

## Online support

### Epilepsy Foundation *eCommunities*

Here you can interact with individuals affected by epilepsy from around the world through threaded discussions and real-time chats. Select from among the following groups:

- Parents Helping Parents – A group for parents and guardians of children with epilepsy.
- Advocacy – This group discusses various advocacy issues, including local, state, and federal efforts.
- Friends, Family, & Loved Ones – Support for those who give support.
- SUDEP (Sudden Unexplained Death in Epilepsy) – A group for education, support and information sharing about this serious subject.
- The Lounge – An informal place to hang out and get to know other members.
- Teen Group – A place just for teens.
- Entitled2Respect – Straight talk for teens about acceptance and epilepsy.
- KidsClub – The friendly puppy Scoop invites kids of all ages to KidsClub. Come out to the Playground! Visit the Funshop! Read some stories. Play games with the puppy.

[www.epilepsyfoundation.org/ecommunities/](http://www.epilepsyfoundation.org/ecommunities/)

### Epilepsytalk

This electronic mailing list, available globally, is centered on pediatric epilepsy and is designed to benefit families who wish to share comments, concerns, and questions regarding their experiences

with pediatric epilepsy and/or other related issues.

[www.epilepsytalk.org](http://www.epilepsytalk.org)

### Epilepsy Support Group on WebMD

This message board includes discussions about the warning signs of an epileptic seizure, which medications are effective, living with the aftermath, and reactions from family and friends.

[www.webmd.com/community/boards](http://www.webmd.com/community/boards)  
(click on ALL BOARDS, then EPILEPSY SUPPORT GROUP or go to [boards.webmd.com/topic.asp?topic\\_id=79](http://boards.webmd.com/topic.asp?topic_id=79))



### Chat rooms on HealingWell.com:

- Epilepsy Forum - Message Boards & Chat – Features interactive message boards and chat rooms. Find support and share information with others.
- Coping With Epilepsy Forum – Discussion forum for anyone affected by epilepsy.
- The Vagus Nerve Stimulation Message Board – Share your experience with VNS.

[www.healingwell.com/pages/Epilepsy/Message\\_Boards\\_and\\_Chat/](http://www.healingwell.com/pages/Epilepsy/Message_Boards_and_Chat/)

## What do I need to know about my child attending school?

Federal laws exist that protect the rights of students to receive a public education, attending schools in their community.



The federal law, the Individuals with Disabilities Education Act (IDEA) 2004, states that all eligible children are entitled to a free and appropriate public education (FAPE) regardless of their disability and should be placed in the least restrictive environment (LRE) with proper supports. Many children with epilepsy/seizure disorder have seizures rarely or not at all and are able to participate in all school activities and may require few if any supports. The legal document that defines the supports a child requires in order to benefit from his/her education is called the Individual Education Plan or IEP. Some students who need special accommodations as a result of their medical condition may not require an IEP but instead may benefit from having a Federal 504 Plan. This plan defines those special accommodations that are needed in school, for ex-

ample, a daily check-in with the nurse for medications or additional time to walk from class to class.

Requests for student evaluations should be put in writing and submitted to the school district director of special education. A parent can request an evaluation by the school to determine their child's eligibility for special education. The school has 15 school calendar days to contact the parent and to get their consent for testing. Once the consent is signed the school has 60 school calendar days to conduct testing, evaluate results, send the results to the parents, and hold the IEP to determine eligibility. If eligible, this meeting would include development of the child's IEP.

Children who have seizures may be socially isolated at school for various reasons. They may experience self-esteem issues and a lower level of achievement. Fortunately, many of these problems can be addressed and prevented when the school develops a good prevention and education plan. School staff, particularly the classroom teacher and the school nurse, can be educated and provide support to the child and other students to improve understanding. Students can benefit the most when the family and school work together. For example, school personnel and the family can monitor the effectiveness of medication as well as any side effects.

The IEP or 504 Plan is developed by

parents and school personnel working together with the student. The services and supports your child receives are based on his/her individual needs. Schools are required by Federal Law to provide the services in the IEP or 504 Plan. If the school is not providing all of the services outlined in the plan, you and your child have the right to file a compliance complaint by calling the Procedural Safeguards Referral Service at 800-926-0648.

For more information on special education, you can get a free copy of “Special Education Rights and Responsibilities” at Protection and Advocacy Inc. (number and website in Resources section below) .

## Resources – IEPs and the 504 Plan

**California Department of Education**  
[www.cde.ca.gov/sp/se/qa/caprntorg.asp](http://www.cde.ca.gov/sp/se/qa/caprntorg.asp)

**California Parent Training and Information Centers**  
[www.taalliance.org/centers/region6.htm](http://www.taalliance.org/centers/region6.htm)

***The Complete IEP Guide: How to Advocate for Your Special Ed, 5th ed.***, by Lawrence M. Siegel (publication information: Berkeley: Nolo, 2007 - ISBN: 978-1-4133-0510-4)

**Families and Advocates Partnership for Education (FAPE), PACER Center**  
 952-838-9000  
 952-838-0190 (TTY)  
 Email [fape@fape.org](mailto:fape@fape.org)  
[www.fape.org](http://www.fape.org) / [www.pacer.org](http://www.pacer.org)  
*FAPE aims to improve the educational outcomes for children with disabilities. This website links families, advocates, and self-advocates to communicate the new focus of*

*the Individuals with Disabilities Education Act (IDEA) .*

### Learning Disabilities Online

[www.ldonline.org](http://www.ldonline.org)  
*This learning disabilities website for parents and teachers has great links to information about learning disabilities.*

### National Dissemination Center for Children with Disabilities (NICHCY)



[www.nichcy.org](http://www.nichcy.org)

### Office of Civil Rights

[www.hhs.gov/ocr/](http://www.hhs.gov/ocr/)

### Protection and Advocacy (PAI)

Special Education Rights and Responsibilities  
 800-776-5746  
[www.pai-ca.org](http://www.pai-ca.org)

Spanish:  

### Sensory Integration Network

[www.sinetwork.org/home/index.html](http://www.sinetwork.org/home/index.html)  
*A website for parents, teachers, and therapists on sensory integration problems. It contains useful pamphlets that can be downloaded to explain Dysfunctional Sensory Integration to teachers.*

### Wrightslaw

[www.wrightslaw.com](http://www.wrightslaw.com)  
*A comprehensive website dedicated to special education, including what rights children and parents have, and how parents can advocate for their children. Both IEPs and Section 504 accommodations are discussed. Any question or concern a parent could have about getting needed services for their child is covered. Most content is written specifically for the site by the Wrights, an attorney and a psychologist, both experts in special education.*

***Wrightslaw: From Emotions to Advocacy - The Special Education Survival Guide, 2nd ed.***, by Pam Wright and Pete Wright (publication information: Hartfield, VA: Harbor House Law Press, 2006 - ISBN: 978-1-892320-09-4 )

## Educating people at school

According to the experts, the best way to prevent misunderstandings about epilepsy at school is to step in early. At the beginning of the year, talk to your child's teacher and school nurse and explain that your child has epilepsy. You may want to take some brochures about the condition. Getting the right information to the right people at school early can make a big difference in your child's school experience. Refer to the next section "How can I educate others about my child's epilepsy/seizure disorder?"

There are products available to teach other children about epilepsy/seizure disorder so that students and friends understand more about seizures. You may want to explore some of the resources listed below.

### Beach Park

[www.epilepsy.org.uk/kids/indexttl.html](http://www.epilepsy.org.uk/kids/indexttl.html)

*Website for kids.*

### KidsClub

[www.epilepsyfoundation.org/kidsclub/nonflash/home/index.html](http://www.epilepsyfoundation.org/kidsclub/nonflash/home/index.html)

*Website for kids.*

### The Kids on the Block, Inc.

800-368-KIDS (5437)



<http://www.kotb.com/kob2.htg/epilepsyfeature.html>

*Educational programming (puppet show and curricula). The Kids on the Block Program on epilepsy was developed in conjunction with the Epilepsy Foundation. It addresses a variety of issues surrounding seizure disorders and provides a basic understanding of seizures, demonstrates*



*seizure first aid, emphasizes the importance of supportive and open friendships, and examines issues of discrimination.*

The following California Family Resource Centers offer *Kids on the Block*:

- Parents Helping Parents  
408-727-5775

Spanish:  

- Rowell Family Empowerment Center  
877-227-3471

Spanish:  



## How can I educate others about my child's epilepsy/seizure disorder?

Often times you will have to educate others about epilepsy/seizure disorder and your child's condition. It is important to make sure that everyone is aware of what to do when a seizure occurs. But you also want to make others feel comfortable when they are around your child. The more knowledge a person has about epilepsy, the more comfortable he or she will feel around your child therefore creating a healthier environment for your child.

When you explain your child's epilepsy, clearly explain the terminology and then explain in simple terms what this means and how seizures might occur. Encourage others to ask questions. Attempt to remove the mystery around your child and his or her seizures. You may want to hand out a brochure or even a video so they can find out a little more on their own and have time to process the information.



The way in which others are informed affects how they treat your child. This goes for your child as well. If you learn to talk about seizure disorder/epilepsy, your child will too. Children are more likely to feel confident about themselves and accept their epilepsy when they know how to talk about it and are not ashamed.

Children and youth with epilepsy must also deal with the psychological and social aspects of the condition. These include public misperceptions and fear of seizures, uncertain occurrence, loss of self-control during the seizure episode, and compliance with medications.

Openness and honesty are the best

ways to combat any stigma surrounding epilepsy/seizure disorder and you will probably find that most people are sympathetic and supportive if they understand the condition and know how they can help.

Please make sure your child is given many opportunities to ask questions and discuss his/her concerns or fears. When possible, he/she also needs to be encouraged to take on some aspects of management of the condition.

You may be getting to know a great deal about epilepsy/seizure disorder, but there are still a lot of people out there who do not. As you educate others about your situation and that of your child, you will help spread the word and reduce the stigma surrounding epilepsy. Please do not take others' lack of knowledge personally.

There are materials available to help make the task of educating others easier. Many find that a good videotape or DVD to hand out to a school teacher or babysitter can help tremendously. For recommendations and to obtain materials, contact your local Epilepsy Foundation affiliate, Parent Training and Information Center (PTIC), or Community Parent Resource Center (CPRC).

Each of the local Epilepsy Foundation affiliates provides seizure first aid training and educational resources, some of which are free of charge.

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## Appendix: Forms

There are a variety of forms available to help keep track of seizures and other information about your child's condition. The following pages contain a selection of such forms. Choose the pages that work for you and make copies so you can easily track your child's records. If you would like to print copies from PDF format, access the *Guide* online at the Epilepsy Foundation of Northern California website.

[www.epilepsyfoundation.org/norcal/](http://www.epilepsyfoundation.org/norcal/)  
(type "Resource Guide" in the SEARCH box)

These forms are also available in Spanish. To obtain a copy, please call the USC UCEDD at 323-361-3830 or access the forms online at the USC UCEDD website.

[www.uscucedd.org](http://www.uscucedd.org)  
(click on PROJECTS, then select EPILEPSY)

### Seizure Records

Seizure Log	F1
Seizure Description Sheet	F2
Seizure Action Plan	F3

### Going to the Doctor

Doctor's Visit Notes / Doctor's Visit Tips	F4
My Child's Profile	F5
Medication Log	F6

### Communications

Encounter Log	F7
Key Contacts	F8





## SEIZURE LOG

**Directions:** Use this form to keep track of your child's seizure activity. Your notes will help health care providers in further treatment of your child.





























Date	Time Seizure Began	Time Seizure Ended	Current Medication and Dose	Description of Seizure	Any Intervention?



## SEIZURE DESCRIPTION SHEET

**Directions:** Please check (✓) what happens (or happened) during your child's seizure and bring this sheet to your child's neurology appointment.

### — DESCRIPTION OF SPELL OR SEIZURE —

 Body	<input type="checkbox"/> whole 	<input type="checkbox"/> right 	<input type="checkbox"/> left 	<input type="checkbox"/> can't tell ?
 Movement	<input type="checkbox"/> jerking 	<input type="checkbox"/> stiffness 	<input type="checkbox"/> jerking and stiffness 	<input type="checkbox"/> can't tell ?
 Eyes	<input type="checkbox"/> up 	<input type="checkbox"/> closed 	<input type="checkbox"/> right → 	<input type="checkbox"/> left ← 
	<input type="checkbox"/> stare 	<input type="checkbox"/> stare and blink 	<input type="checkbox"/> no change 	<input type="checkbox"/> can't tell ?
 Skin Color	<input type="checkbox"/> blue 	<input type="checkbox"/> no change 	<input type="checkbox"/> can't tell ?	
 Accident	<input type="checkbox"/> pee – pee 	<input type="checkbox"/> poop 	<input type="checkbox"/> none	<input type="checkbox"/> can't tell ?
 Mouth	<input type="checkbox"/> dry 	<input type="checkbox"/> drool 	<input type="checkbox"/> foam 	<input type="checkbox"/> bite tongue 
	<input type="checkbox"/> can't tell ?			
 How Often	<input type="checkbox"/> daily <input type="checkbox"/> weekly <input type="checkbox"/> monthly <input type="checkbox"/> other: _____			

### — AFTER SEIZURE OR SPELL —

<input type="checkbox"/> asleep	<input type="checkbox"/> drowsy	<input type="checkbox"/> alert	<input type="checkbox"/> confused	<input type="checkbox"/> paralyzed
				



# SEIZURE ACTION FORM

This form provides information to assist in the safe care of this child during a seizure.

Name: \_\_\_\_\_ DOB \_\_\_\_\_ Age \_\_\_\_\_

Parent/Guardian Name: \_\_\_\_\_ Home \_\_\_\_\_ Work \_\_\_\_\_ Cell \_\_\_\_\_

Other Emergency Contact: \_\_\_\_\_ Home \_\_\_\_\_ Work \_\_\_\_\_ Cell \_\_\_\_\_

Primary Care Doctor: \_\_\_\_\_ Office \_\_\_\_\_ Fax \_\_\_\_\_ Emergency \_\_\_\_\_

Neurologist: \_\_\_\_\_ Office \_\_\_\_\_ Fax \_\_\_\_\_ Emergency \_\_\_\_\_

## SEIZURE INFORMATION

At what age did child have first seizure? \_\_\_\_\_

SEIZURE TYPE	LENGTH	FREQUENCY	DESCRIPTION

Does child act differently before seizure?  Yes  No Explain: \_\_\_\_\_

How does child act after a seizure is over? \_\_\_\_\_

How do other illnesses affect child's seizures? \_\_\_\_\_

## SEIZURE FIRST AID

In addition to Basic Seizure First Aid, what other procedures should be done when child has a seizure?

Will child need to leave classroom?  Yes  No

Should an extra change of clothes be kept at school?  Yes  No

If "yes," where is extra change of clothes kept? \_\_\_\_\_

Does child have a VNS?  Yes  No

If "yes," when should magnet be used? \_\_\_\_\_

### BASIC SEIZURE FIRST AID:

- Stay calm & track time
  - Keep child safe
  - Do not restrain
  - Do not put anything in mouth
  - Stay with child until fully conscious
  - Record seizure in log
  - Turn child on side
- For tonic-clonic seizure:
- Make sure head is protected
  - Keep airway open/watch breathing

A seizure is generally considered an EMERGENCY when:

- A convulsive (tonic-clonic) seizure lasts longer than 5 minutes
- Student has repeated seizures without regaining consciousness
- Student has a first time seizure
- Student is injured or has diabetes
- Student has breathing difficulties

## SEIZURE EMERGENCY

A seizure emergency for this child is: \_\_\_\_\_

**PROTOCOL**

Administer emergency medication listed below.

Contact school nurse at: \_\_\_\_\_

If an ambulance is required, transport to: \_\_\_\_\_

Notify parent at: \_\_\_\_\_

Notify emergency contact at: \_\_\_\_\_

Notify doctor: \_\_\_\_\_ Doctor's name: \_\_\_\_\_ Phone: \_\_\_\_\_

## EMERGENCY MEDICATION PLAN

MEDICATION	DOSAGE	METHOD	WHEN TO USE

## SPECIAL CONSIDERATIONS/ SAFETY PRECAUTIONS

(with school activities, sports, trips, etc.) \_\_\_\_\_

Doctor Name & Signature: \_\_\_\_\_ / \_\_\_\_\_ Date: \_\_\_\_\_

Parent/Guardian Signature: \_\_\_\_\_ Date: \_\_\_\_\_

School Nurse Signature: \_\_\_\_\_ Date: \_\_\_\_\_





## DOCTOR'S VISIT NOTES

**Directions:** Use this form to remind you about questions you have for your child's doctor and to record your own notes from this visit.

Date of Appointment:	
Doctor's Name / Phone Number:	

### Before the Visit

1. Reason for today's visit:	
2. How long has this been going on?	
3. What makes it better/worse?	
4. What have you tried so far?	
5. What do you hope will happen at this visit?	

### Notes from the Visit

1. What is the diagnosis?	
2. Does my child need a prescription? If yes, what is the medication and dosage?	
3. What should the medication do and when?	
4. Is there anything I should watch out for / side effects?	
5. If no medication is needed, what should I do for my child to resolve the issue?	
6. What should I do if my child gets sick or has more symptoms?	
7. Where can I get more information?	

## DOCTOR'S VISIT TIPS

### Get ready

1. Bring any information that you have about your child. (My Child's Profile)
2. Bring pen/pencil and paper to take notes.
3. Check your data and be specific about all changes in your child's health status. (Seizure Log, Seizure Description Sheet)
4. Have a list of all medications your child is currently using, including over-the-counter drugs. (Medication Log)
5. Have a list of reactions your child has experienced from any medications, prescribed or over-the-counter.
6. Write all of your questions down before visiting the doctor. (Doctor's Visit Notes)

### Tell the doctor:

1. How your child has been doing.
2. Information about successes and setbacks.
3. Detailed information about changes and symptoms that are different from your child's normal status.
4. What you are concerned about.
5. When the symptoms started changing.
6. How often and when the symptoms occurred.
7. What you have tried to relieve the symptoms and your child's response.

### Don't leave the doctor's office without:

1. Instructions and name(s) for new and old medication(s).
2. Asking how long the child will be on medication and whether there are refills.
3. Asking about possible side effects or cross-reactions of medication(s).
4. Asking what the child can eat with new medication(s).
5. Asking if you need authorization before filling the prescription for your specific insurance provider.
6. Understanding all follow-up questions including how to report changes in symptoms.
7. Asking the doctor if you need a follow-up appointment.
8. Making the next appointment, if needed.

## MY CHILD'S PROFILE

<b>Name</b>			
<b>Date of Birth</b>			
<b>Height</b>		<b>Eye Color</b>	
<b>Weight</b>		<b>Blood Type</b>	
<b>Languages Spoken</b>		<b>Sex</b>	<input type="radio"/> female <input type="radio"/> male
<b>Telephone</b>	Home	Work	Mobile
<b>Address</b>			
<b>Parent or Guardian</b>			
<b>Telephone</b>	Home	Work	Mobile
<b>Address</b>			
<b>Parent or Guardian</b>			
<b>Telephone</b>	Home	Work	Mobile
<b>Address</b>			
<b>Emergency Contact</b>			
<b>Relation</b>			
<b>Telephone</b>			
<b>PRIMARY Health Insurance</b>			
<b>Health Insurance Plan</b>			
<b>Plan Number</b>			
<b>SECONDARY Health Insurance</b>			
<b>Health Insurance Plan</b>			
<b>Plan Number</b>			







## ENCOUNTER LOG

Date	Name or Agency/Phone	Purpose	Type	Result
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In Person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In Person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In Person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In Person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In Person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In Person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In Person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In Person <input type="checkbox"/> Email <input type="checkbox"/> Fax	
			<input type="checkbox"/> Telephone <input type="checkbox"/> Written <input type="checkbox"/> In Person <input type="checkbox"/> Email <input type="checkbox"/> Fax	







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Childrens Hospital Los Angeles



#### ACCESS THE *GUIDE* ONLINE

An electronic version (PDF format) of the *Guide* can be accessed via the internet at the Epilepsy Foundation of Northern California website:

[www.epilepsyfoundation.org/norcal/](http://www.epilepsyfoundation.org/norcal/)

(type "Resource Guide" in the SEARCH box)

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