Epilepsy and Seizure Disorders:

A Resource Guide for Parents

Table of Contents

Section One: Understanding Epilepsy / Seizure Disorder

Section Two: Health Care

Section Three: Community Care

Charts and Forms

Quick Tips

What is epilepsy/seizure disorder?

The brain contains billions 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 4.9 million Americans have epilepsy. Of the 200,000 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.

What are the different kinds of epilepsy / seizure disorder?

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

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. This is known as a partial seizure that secondarily generalizes.

For more information on seizure types please refer to the chart on page 16.

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 several 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.

For more information regarding diagnosis please see chart on page 17.

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

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
- Dehydration
- Poor Diet
- Inactivity

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). Other treatment therapies are being tested, but have not yet been FDA approved.

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.

For more information regarding your prescriptions as well as medication tips see page 19.

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.

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.

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 all observations about the seizure or subsequent behavior so that you can tell your doctor exactly what happened. 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. 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.

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.

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.

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.

Local epilepsy organizations may be able to provide the names of doctors who accept private insurance, Medicaid, Medicare 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 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 are 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.

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. Finally, commercial insurance may also include a mental health benefit. Information about this can be obtained from your member services department (check your health insurance card for the number).

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.

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

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

Health Insurance Portability and Accountability Act (HIPAA) protects your privacy health insurance information. If you suspect your HIPAA rights are being violated you should file a report with your state Insurance Commissioner.

ME: 207-582-8707 NH: 800-852-3416

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 team, you may feel overwhelmed and confused. Health care professionals have recognized the need to partner with families in caring for children, 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.

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.

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 Epilepsy Foundation.

Online support

Epilepsy Foundation *eCommunities*
Here your kids can interact with others 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.
- 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.
- Kids Club –The friendly puppy Scoop invites kids of all ages to Kids Club. Come out to the Playground! Visit the Funshop! Read some stories. Play games with the puppy. Go to the Epilepsy Foundations Homepage to enter.

Do you know 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. CPR is rarely used when a child is seizing.

Please refer to page 18 for first aid protocol.

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

Remember to tell others about the appropriate first aid for your child. 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.

Seizure Action Plan

Be sure that your child is protected and safe everywhere he or she goes by having a Seizure Action Plan. It outlines emergency medical care, medications, contacts as well as outlining your child' s seizures and triggers. Ask your neurologist about creating a seizure action plan for you child. They can be distributed to teachers, school nurses, family members, coaches and babysitters. There is a Seizure Action Plan located on page 30.

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. 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 example, 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 45 school calendar days in NH and 60 in ME 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.

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. Be sure to ask for a “Parent Rights” Booklet from your school district. If you feel your child is providing all the services outlined in the plan, this booklet will outline how to file a complaint.

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. You will probably find that most people are sympathetic and supportive if they understand the condition and know how they can help.

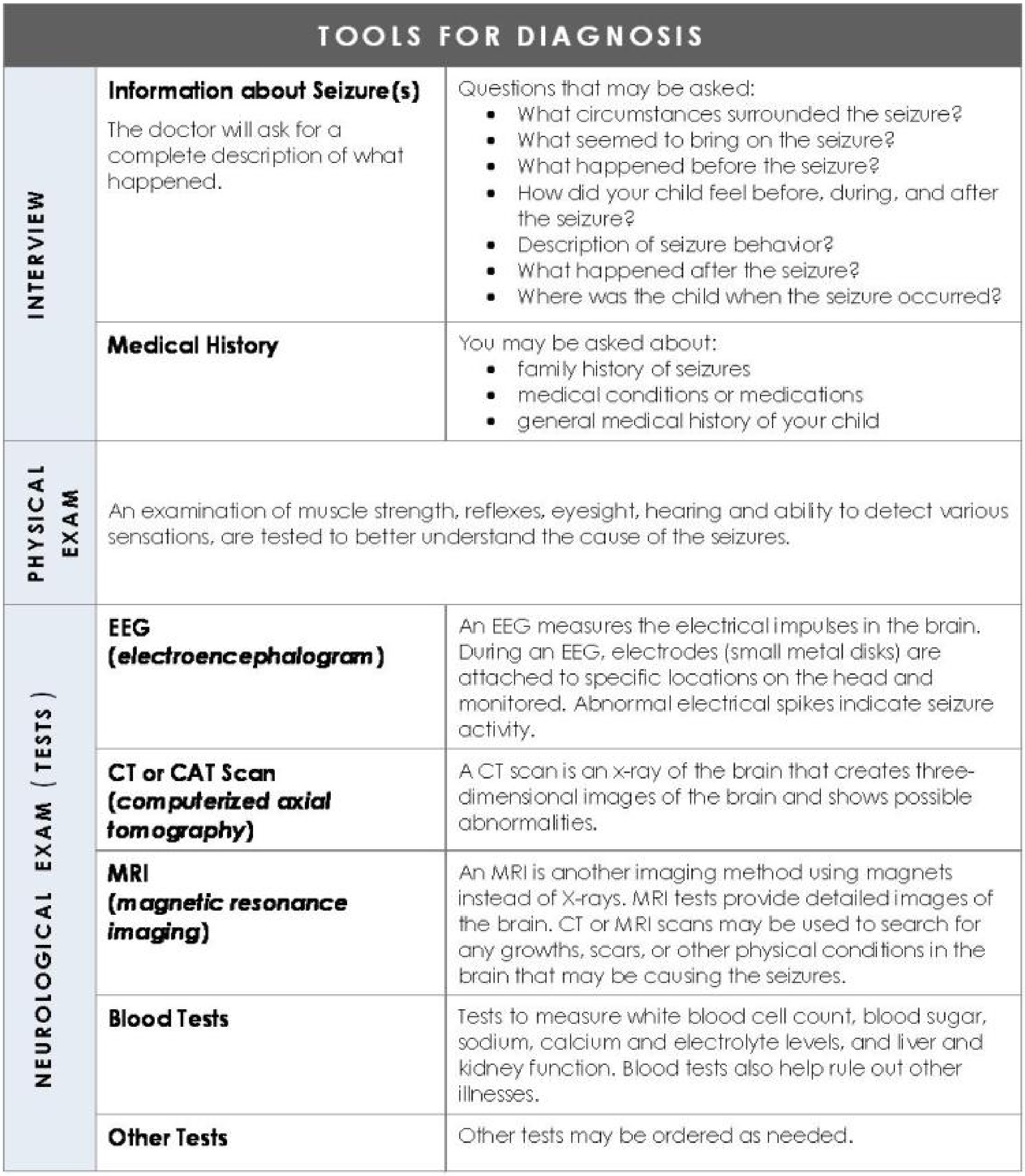
You may be getting to know a great deal about epilepsy/seizure disorder, but there are still a lot of people out there who do not. As you educate others about your situation and that of your child, you will help spread the word and reduce the stigma surrounding epilepsy.

Seizure Classification

SEIZURE TYPE		DESCRIPTION
GENERALIZED	**Tonic-clonic or Grand Mal** **(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.
	Absence or Petit Mal **(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.
	Myoclonic or Jerks **(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.
	Tonic and Atonic **(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.
	Status Epilepticus **(loss of consciousness)**	This seizure is characterized by frequent, long-lasting seizures without regaining consciousness between attacks.
PARTIAL	**Simple** **(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.
	Complex **(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.

Epilepsy Action （British Epilepsy Association）, Epilepsy Information: Seizure Types, http://www.epilepsy.org.uk/info/chart.html （August 29, 2007）.

Diagnostic Tips



TOOLS FOR DIAGNOSIS		
INTERVIEW	**Information about Seizure(s)** The doctor will ask for a complete description of what happened.	Questions that may be asked: • What circumstances surrounded the seizure? • What seemed to bring on the seizure? • What happened before the seizure? • How did your child feel before, during, and after the seizure? • Description of seizure behavior? • What happened after the seizure? • Where was the child when the seizure occurred?
	Medical History	You may be asked about: • family history of seizures • medical conditions or medications • general medical history of your child
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)	**EEG (*electroencephalogram*)**	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.
	CT or CAT Scan (*computerized axial tomography*)	A CT scan is an x-ray of the brain that creates three-dimensional images of the brain and shows possible abnormalities.
	MRI (*magnetic resonance imaging*)	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.
	Blood Tests	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.
	Other Tests	Other tests may be ordered as needed.

Chart appears from WebMD, Diagnosing Epilepsy, http://www.webmd.com/epilepsy/guide/diagnosing-epilepsy (August 29, 2007).

FIRST AID FOR SEIZURES[15,16]

	Seizure Type	What to Do
GENERALIZED	**Tonic-Clonic or Grand Mal** (loss of consciousness)	• 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. • Do not put anything in child's mouth or give liquids or medications during or immediately after the seizure. • Do not try to hold the child's tongue; it cannot be swallowed. • Do not restrain movement. • 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. • Reassure the child when consciousness returns. • 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. • 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.
	Absence or Petit Mal (loss of consciousness)	• Observe the child carefully. • Reassure the child if he or she is frightened or confused. • Try to count and record episodes. • No first aid is necessary, but if this is the first observation of an absence seizure, medical evaluation is recommended.
	Myoclonic or Jerks (no loss of consciousness)	• Speak calmly to the child and other children around him or her. • If the child is walking, guide him or her gently to a safe place. • 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. • If the seizure is a first occurrence, a medical check-up is recommended. • First aid is usually not needed. However, a child having a myoclonic seizure for the first time should receive a thorough medical evaluation.
	Tonic and Atonic or Akinetic (loss of consciousness)	• Comfort the child and check to see if he or she is hurt. A medical check- up is recommended. • 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.
	Status Epilepticus (loss of consciousness)	• This condition requires immediate medical attention. Call for medical help. • Do not attempt to transport an actively seizing child in your car unless an ambulance is not available. • If the child has had this type of seizure before, follow advice specifically given by the child's doctor.
PARTIAL	**Simple** (no loss of consciousness)	• No first aid necessary, but if this is the first observation of the seizure, medical evaluation is recommended.
	Complex (loss of consciousness)	• Speak calmly to the child and other children around him or her. • If the child is walking, guide him or her gently to a safe place. • 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. • 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.

Pharmaceutical Contact Information

Abbott Laboratories (*Depakote)*
800-222-6885
www.helpingpatients.org

Cephalon, Inc (*Gabitril*)
866-209-7589

Eisai *(Zonegran*)
866-694-2550

GlaxoSmithKline (*Lamictal*)
888-825-5249
www.bridgestoaccess.com

Novartis (*Tegretol, Trileptal*)
800-277-2254
www.pharma.us.novartis.com/novartis/pap/pap.jsp

Ortho-McNeil (*Topamax*)
877-937-9682 / 800-652-6227
www.access2wellness.com/a2w/patient-pap.html

Pfizer (*Dilantin, Neurontin, Zarontin*)
866-776-3700
www.pfizerhelpfulanswers.com

UCB Pharma (*Keppra*)
800-477-7877

Valeant (*Diastat, Mysoline)*
800-511-2120

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.
- 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.
- 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.

Medication Assistance Programs

Access 2 Wellness

Access2wellness provides access to one of the broadest selections of assistance programs that offer more than 1,000 prescription medications, for free or at a discount, to those who qualify.
1-866-317-2775
www.access2wellness.com

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

Rx Assist

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

Rx Hope

A patient assistance company partially funded by the pharmaceutical manufacturers. It promises to speed requests for no-cost medications.
800-511-2120
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

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

Local Resources
New Hampshire

Medicaid
NH DHHS Office of Medicaid
and Business & Policy
97 Pleasant St
Concord, NH 03301
603-271-5254
www.dhhs.state.nh.us/
medicaidprogram.htm

Healthy Kids Gold
2 Pillbury St, Suite 300
Concord, NH 03301
877-464-2447
www.nhhealthykids.com/
programs_gold.php

New Hampshire Family Voices
129 Pleasant St., Thayer Bldg.
Concord, NH 03301
603-271-4525
800-852-3345 ext 4525
www.nhfv.org

Bureau of Developmental Services
105 Pleasant St
Concord, NH 03301
603-271-5043
www.dhhs.stat.nh.us/dhhs/bds/default.htm

Parent to Parent of New Hampshire
12 Flynn St.
Lebanon, NH 03766
800-698-5465
www.parenttoparentnh.org

Special Medical Services
97 Pleasant St
Concord, NH 03301
603-271-4488
800-735-2964
www.dhhs.state.nh.us/dhhs/
specialmedsrvcs/default.htm

Partners in Health
129 Pleasant St. - Thayer Building
Concord, NH 03301
800-656-3333
603-271-4902
Aml'esperance@dhhs.state.nh.us

Parent Information Center
PO Box 2405
Concord, NH 03302
603-224-7005
www.parentinformationcenter.org

Local Resources
Maine

MaineCare
11 State House Station
Augusta, ME 04333
207-287-9202
800-606-0215
www.maine.gov/dhhs/oms/

Southern Maine Parent Awareness
886 Maine Street Suite 303
Midtown Mall, 2nd Floor
Sanford, ME 04073
800-564-9696
www.somepa.org

C.A.R.E.S., Inc.
47 Water St., Suite #104
Hallowell, ME 04347
800-773-7055
www.caresinc.org

C.A.R.E.S. has a proven track record in areas such as advocacy, case management, program evaluation and policy development.

Maine Parent Federation
PO Box 2067
Augusta ME 04338
207-623-2144
1800-870-7746
www.mpf.org/projects/familysupport.htm

Maine Parent Federation / SPIN
PO Box 2067
Augusta, ME 04338
207-623-2144
www.mpf.org/projects/spin.htm

Maine Department of Education
23 State House Station
Augusta ME 04333-0023
207-624-6700
www.maine.gov/education

Consumers for Affordable HealthCare
PO Box 2490
Augusta ME 04338-2490
800-838-0388
207-622-7045
www.mainecahc.org

Penquis CAP
262 Harlow Street
Bangor ME 04401
1800-215-4942
www.penquis.org

The Lynx provides transportation services for residents of Penobscot and Piscataquis Counties.

Children ’ s Center
1 Alden Avenue
Augusta ME 04330
207-626-3497
www.childrenscenteraugusta.com

National Resources

Epilepsy Foundation
8301 Professional Place, East
Landover, MD 20785
800-332-1000
www.epilepsyfoundation.org/drsearch.com
Use this web address to go directly to the page that offers an online search for doctors near you.

Epilepsy Foundation of Massachusetts and Rhode Island
540 Gallivan Blvd
Boston, MA 02124
617-506-6041
www.efmri.org

American Epilepsy Society (AES)
342 N. Main St.
West Hartford, CT 0611-2507
860-586-7505
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
The NAEC is a non-profit trade association whose members include more than 60 specialized epilepsy centers.

Epilepsy Foundation of Vermont
P.O. Box 6292
Rutland, VT 05702
802-775-1686
www.epilepsyvt.org

National Resources

Families and Advocates Partnership for Education (F APE)

PACER Center
8161 Normandale Blvd
Bloomington, MN 55437
952-838-9000
www.fape.org / www.pacer.org
FAPE aims to improve the educational outcomes for children with disabilities.

Charlie Foundation to Help Cure Pediatric Epilepsy

1223 Wilshire Blvd.
Suite #815
Santa Monica, CA 90403
www.charliefoundation.org
310-393-2347

National Family Caregivers Association

10400 Connecticut Avenue
Suite 500
Kensington, MD 20895
www.thefamilycaregiver.org
800-896-3650

Epilepsy.com

Epilepsy Therapy Project
P.O. Box 742
Middleburg, VA 20118
540-687-8077
www.epilepsy.com
Epilepsy.com provides in-depth information and community for people living with epilepsy.

Camp WeeKanTu

Crossroads for Kids - Camp Wing
742 Keene St
Duxbury, MA 02332
617-506-6041
Camp WeeKanTu is can a camp designed to give kids with epilepsy a safe, fun and welcoming summer camp environment

Online Resources

Epilepsy Classroom

www.epilepsyclassroom.com/home/index.aspx

Created for parents and teachers, this site – through the EFA provides advice, resources, tools and parent resources to help your child excel in the classroom.

Talk About It

www.talkaboutit.org/

TalkAboutIt.org is a new star-studded Web site created to educate the world about seizures and epilepsy on behalf of the 50 million people around the globe, who are coping with the condition.

Epilepsy Support Group Meetings

www.epilepsyfoundation.org

All meetings can be checked on the Advocacy forum of E-Communities .
On-line support is available through the website by free registration. All are welcome to attend support group meetings including family and friends.

Epilepsy and My Child

www.epilepsyandmychild.org

A comprehensive website for parents. Whether your child was just diagnosed, or you have specific concerns about medications, getting support at school, or another issue, our goal is to provide the information you need.

Epilepsy Action

www.epilepsy.org.uk/info/parents.html

Information for parents, family, friends or children; the UK' s Epilepsy Action website covers it all. This constantly updated site highlights new research, medications and international epilepsy news in an easy to read format

CURE / Citizens United in Research in Epilepsy

www.cureepilepsy.org

Keep up to date on the latest research in the field of Epilepsy. The site provides links to various resource centers, research grants, national advocacy efforts and efforts to increase public awareness through various media outlets.

Seizure Action Plan:

Name:	
Childs DOB: / /	Childs Weight: Date Taken:
Parents: Email: Phone:	Emergency Contact: Relation: Phone:
Pediatrician: Phone: Email:	Neurologist: Phone: Email:

Seizure Information:

Seizure Type:	What Happens:	Length:	Frequency:

Triggers:

Daily Seizure Medication:

Medications:	How Much:	How Often:

Diet:	Special Instructions:	When Started:

Devices Type:	Special Instructions:	Date Implanted:	Serial # / Model #:

Seizure First Aid:

☐ Keep calm, provide reassurance, remove bystanders
☐ Keep airway clear, turn on side if possible, nothing in mouth
☐ Keep safe, remove objects, do not restrain
☐ Time, observe, record what happens
☐ Stay with person until recovered from seizure
☐ Other care needed:

Emergency Care / Rescue Treatments:

Name:	Amount to Give:	When to Give:	How to Give:

Call 911 or Seek Emergency Medical Attention If:

☐ Generalized seizure longer than 5 minutes
☐ Two or more seizures without recovering between seizures
☐ " Emergency Care / Rescue Treatments " don't work
☐ Injury occurs or is suspected, or seizures occurs in water
☐ Breathing, heart rate or behavior doesn't return to normal
☐ Unexplained fever or pain, hours or few days after a seizure

Authorizations:

I have read this action plan and agree with the information . I also give permission for the school nurse to discuss the management of epilepsy with members of the medical team.

Parent / Guardian Signature _ **Date** _ _ _ / _ _ _/ _ _ _

The school nurse may administer medications per this action:

Provider Signature _ **Date** _ _ _/ _ _ _/ _ _ _

In general, children with seizure disorders should not be limited in their activities. However, climbing to heights without a harness or swimming should always be closely monitored.

Patient Information Sheet

Please check what happens (or happened) during your child's seizure

DESCRIPTION OF SPELL OR SEIZURE / DESCRIPCIÓN DEL ATAQUE O CONVULSIÓN

Body / Cuerpo	☐ whole/ entero	☐ right/ lado derecho	☐ left lado izquierdo	☐ can't tell no sabría decir ?
Movement/ Movimiento	☐ jerking/ espasmos	☐ stiffness/ rigidez	☐ jerking and stiffness/ espasmos y rigidez &	☐ can't tell no sabría decir ?
Eyes Ojos	☐ up/ ↑ en blanco	ed/ ados	☐ right/ a la	☐ left/ ← a la izquierda
	☐ stare/ mirada fija	☐ stare and blink/ mirada fija y parpadeo → →	☐ no change/ sin cambio	☐ can't tell/ no sabría decir ?
Skin Color Color de piel	☐ blue/ morada	☐ no change/ sin cambio		☐ can't tell/ no sabría decir ?
Accident Accidente	☐ pee – pee orina	☐ poop popo	☐ none ninguno	☐ can't tell/ no sabría decir ?
Mouth Boca	☐ dry seca	☐ drool babea	☐ foam le sale espuma	☐ bite tongue se muerde la lengua
				☐ can't tell/ no sabría decir ?
How Often / Frecuencia	☐ daily diariamente	☐ weekly semanalmente	☐ monthly mensualmente	☐ other otro :

AFTER SEIZURE OR SPELL / DESPUÉS DEL ATAQUE O CONVULSIÓN

☐ asleep/ se duerme

z z z

☐ drowsy/ soñoliento

☐ alert/ alerta

☐ confused/ confundido

? ? ?

☐ paralyzed paralizado

Quick Tips: Antiepileptic Medicines

The AED needs to be taken every day to prevent seizures. Here are some tips for remembering to give medicine:

- Give the medicine at the same time everyday as part of your child's daily routine. Have your child take it with a meal or when teeth are brushed.
- Let your child put a sticker on the calendar whenever the medicine is taken. This provides a fun reward for your child. It is also a good way to keep track of the medicine doses.
- Use a pill box to help check that a dose wasn't forgotten.

It is important to not miss any medicine doses.

- If you forget a dose, give the medicine as soon as you remember. Do not give 2 doses at the same time (unless your doctor says this is okay to do.) Give the next dose at least 4 hours later. Do not try to catch up on missed doses.
- If your child throws up the medicine within 20-30 minutes of giving the dose, try to give the does as soon as your child is able to keep down small amounts of clear liquids. If your child throws up the dose a second time, don't repeat the dose. Call your doctor or nurse for help.

If your child becomes ill or has side effects while you are either increasing or decreasing the AED medicine, call your doctor or nurse. They will give you instructions about the plan for the next medicine change.

Some medicines, including over the counter medicines may affect your child's AED medicines by making it too strong or too weak. Check with your pharmacist to be sure that other medicines are okay to take with the AED medicine. It is okay to use acetaminophen (Tylenol®) or ibuprofen when your child is taking an antiseizure medicine.

It is good idea to carry a list of your child's medications with you. This list should include any vitamins, supplements, or home remedies.

When your child is old enough, help them learn to remember to take their medicine on their own. A good time to start is when your child is between 5th and 6th grade. You can start by having them fill their pillbox every week. Let your child take the medicine with you double-checking that it wasn't forgotten.

Quick Tips: Lifestyle Factors

Certain things may make seizures occur more easily. These are called "triggers." Some triggers can be avoided, such as:

- Lack of Sleep
- Forgetting to take your medication
- Drinking Alcohol

Other triggers, such as getting sick or for women, getting your menstrual period, can't be avoided - they are just part of life. Often taking good care of your body can help to avoid some of the seizure triggers.

- Eat 3 well balanced meals every day.
- Get regular exercise to keep the body healthy. Being involved in sports or any fun activities are good ways to get exercise. Talk with your doctor or nurse about taking part in physical activity.
- Get a full night's sleep. Children should get at least 10-12 hours of sleep a night, and teenagers should get at least 8-10.
- Avoid caffeine close to bedtime. Caffeine may make it harder to get a proper night's sleep. Remember that chocolate, most sodas, teas and coffee contain caffeine, especially energy drinks.

As your child gets older, help them learn to take part in their own health care.

- When your child turns 8, begin talking to them about the changes that will happen in clinic. Tell your child that doctors and nurses will start to ask them questions directly. This will let your child get comfortable answering questions while they have the safety of a parent in the room.
- Work with your child at home to take an active role in their care. Gently encourage independence, but know that it will take time.
- When your child is 14, encourage them to see the health care team without you for most of the visit. You can join the visit at the end to review any new information. This will also give you a chance to ask any questions or address concerns you may have.

Quick Tips: Travel

Advance Planning

- Call the airlines and explain your needs. Ask what accommodations they provide. Ask about guidelines for carry on medicines.
- If you are traveling to theme parks or other locations, call and ask what help they provide.
- Pick out snacks, books or toys with your child to help them enjoy the trip.

Put together a packet that has phone numbers you may need, including your child's:

- Primary care provider
- Neurology provider
- Pharmacist
- Emergency family contact who knows your child's medical history
- Pharmacy and hospital where you will be traveling

Medication

- Be sure to have your prescriptions filled and picked up before you leave home.
- Get prescriptions refilled 2-3 weeks before the start of your vacation to be sure you have enough to take with you.
- If needed, call your insurance company to see if they will give you advance doses so you will not run out.
- For air travel, carry two supplies of medicines with you. Put one in your carry-on and the other in your checked baggage. If your child uses Diastat®, keep this in your carry-on bag.
- Carry a written list of medicines and doses. This is called a Home Medication List.
- Bring your pharmacy phone number from home. If needed, they can help you with possible insurance issues at a new pharmacy.
- If your child is not using a rescue medicine now, such as Diastat®, call your nurse or doctor to see if it is needed for the trip.

Emergency Care

Ask for and carry a current emergency care plan signed by your care provider. Your child should wear a medical bracelet or necklace stating they have epilepsy. Also include any allergies on the bracelet/necklace or shoetag. Everyone traveling with your child should know seizure first aid. Know what to do and what not to do during a seizure and how to describe the seizures.

Quick Tips: Travel

Vagal Nerve Stimulator

- Carry the registration card with you in case it is needed at the airport.
- If airline or tourist attraction screening is needed, ask to have your child manually searched. This will avoid setting off the security screening device.

Ketogenic Diet

- Ask to have a refrigerator in your hotel room to store special diet foods.
- Make enough meals to have on hand during the time that you are traveling. Plan extra meals in case you are delayed by weather. Be sure to take an insulated carrier and enough cooling packs to keep food that you carrying safe.
- For travel out of the country, you will probably need a letter from the doctor to take foods for the diet in and out of the country.

At your destination

- Check for the location and phone number of a pharmacy and hospital near you.
- Call ahead for advance seating at restaurants and local attractions.
- Have a hospital bag put together ahead of time so that you will have everything that you need. Include a change of clothes, money, the emergency care plan and your care note book or notes about your child ' s care.
- If you need to visit the Emergency Room while on vacation, the following tips may help make it a smooth visit.
- Carry an emergency care plan for your care provider. The plan should include the doses of emergency medicines already calculated for your child ' s weight. This care plan should be signed by your care provider.
- Bring notes on what has been done in the past to control your child ' s seizures. Include information on what has not worked for your child.
- Be an advocate. You know your child ' s care best.
- Bring your care provider's contact information with you.

References

Patricia E. McGoldrick and Steven M. Wolf, Parents' Guide: When the Seizures Don't Stop...Why - and What to Do Next (Abbott Laboratories Neuroscience, December 2004). Available at http://www.wehealny.org/services/bi_pedsepilepsycenter/seizure%20book.pdf (August 29, 2007).

National Dissemination Center for Children with Disabilities (NICHY), Disability Fact Sheet – No.6 (Epilepsy), January 2004, http://www.nichcy.org/pubs/factshe/fs6.pdf (August 29, 2007).

Eric H. Chudler, Epilepsy: Types of Epilepsy, http://faculty.washington.edu/chudler/epi.html (August 29, 2007).

Epilepsy Action (British Epilepsy Association), Epilepsy Information: Seizure Types, http://www.epilepsy.org.uk/info/chart.html (August 29, 2007).

WebMD, Diagnosing Epilepsy, http://www.webmd.com/epilepsy/guide/diagnosing-epilepsy (August 29, 2007).

Epilepsy Foundation of America, Inc., Seizures and Epilepsy, H.O.P.E. Mentoring Program, 2003.

Patricia E. McGoldrick and Steven M. Wolf, Parents' Guide: When the Seizures Don't Stop...Why - and What to Do Next (Abbott Laboratories Neuroscience, December 2004). Available at http://www.wehealny.org/services/bi_pedsepilepsycenter/seizure%20book.pdf (August 29, 2007).

Department of Health and Human Services, Centers for Disease Control and Prevention and The Epilepsy Foundation, Reach Out: A Guide for Teens with Epilepsy. Available at http://www.cdc.gov/epilepsy/pdfs/brochure.pdf (August 29, 2007).

Finding a Cure for Epilepsy and Seizures (FACES), NYU Medical Center, Pediatric Epilepsy Resource Guide. Available at http://www.med.nyu.edu/faces/assets/pediatric_handbook2005.pdf (August 29, 2007).

US Department of Labor, Health Plans & Benefits, Portability of Health Coverage (HIPAA), http://www.dol.gov/dol/topic/health-plans/portability.htm (August 29, 2007).

US Department of Health and Human Services, Office for Civil Rights, Fact Sheet: Privacy and Your Health Information, http://www.hhs.gov/ocr/hipaa/consumer_summary.pdf (August 29, 2007).

Epilepsy.com, Diagnosis 101: The Basics, http://www.epilepsy.com/101/diag101_best.html (August 27, 2007).

American Academy of Pediatrics, The National Center of Medical Home Initiatives for Children with Special Needs, http://www.medicalhomeinfo.org/tools/familyindex.html (September 6, 2007).

Cynthia Haines, ed., WebMD, Epilepsy: First Aid for Seizures, October 2004, http://www.medicinenet.com/first_aid_for_seizures/article.htm (August 29, 2007).

Epilepsy.com, Treatment: Seizure First Aid, http://www.epilepsy.com/epilepsy/firstaid.html (August 29, 2007).

Photographs appear courtesy of Dartmouth-Hitchcock Medical Center   Originally Published September 2007 by USC University Center for Excellence in Developmental Disabilities, Childrens Hospital Los Angeles. Edited and recreated by Hood Center for Children and Families through Dartmouth Medical School in 2009. Quick Tips are Tip Sheets made possible through the generosity of the Wisconsin Seizure Control Network and HRSA Grant (#1H98MC039007-02-00). The content does not express the views of HRSA and are expressly the views of the authors.

Epilepsy and Seizure Disorders: A Resource Guide for Parents was developed with funding from the federal Maternal and Child Health Bureau, Health Services and Resources Administration under grant #H98MCO3905, funded to the USC University Center for Excellence in Developmental Disabilities, Childrens Hospital Los Angeles, through its initiative, *Project Access: Improving Care for Children with Epileps*y. Support was also provided by two other partners in *Project Access*: the National Initiative for Children's Healthcare Quality (NICHQ), under grant # U23MC038893, and the Epilepsy Foundation, under grant # U23MC03909. Recreated by the Hood Center for Children and Families as part of Dartmouth Medical School.