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Informational Resource Guide

E P I L E P S Y

West Virginia University Children's Hospital

EPILEPSY FOUNDATION®
Not another moment lost to seizures™

CENTER FOR EXCELLENCE IN DISABILITIES
"Commitment To Excellence"
West Virginia University

Table of Contents

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GUIDELINES FOR PEDIATRIC NEUROLOGY CLINIC PHONE CALLS

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EMERGENCY PHONE CALLS:

If your child is having a medical emergency that needs to be taken care of immediately, please call 911 to reach your local emergency medical team.

Please call your child's pediatrician or family doctor for routine health problems or if your child is sick.

PHONE CALLS: If you have questions or concerns about your child's neurological problem, please call the Neurology Office by 1:00 p.m. Monday through Friday, when possible. This makes it easier for the nurse to return your phone call on the same day.

Please give us:

- Your child's first and last names and date of birth. (Please spell out names.)
- Your first and last name.
- Your daytime and early evening phone numbers, including your cell phone number(s), and when you can be reached at those numbers.

Please let us know the reason for your call. Be specific whenever possible.

REFILLS: Medicine refills are done Monday through Friday 8am - 4pm.

Call for the refill at least one week before the medicine is gone. Call 304-598-4835, press option 2, then option 1 to leave a message on voice mail for the prescription needed.

Or

You can request that your pharmacy fax us a refill request **at least one week** before you run out of medicine. **Fax the request to 304-598-6061.**

Please give us:

- Your child's first and last names and date of birth. (Please spell out names.)
- The name, dose and how often your child takes the medicine. (Please spell out the name.)
- The form such as a liquid, tablet or sprinkle.
- The name and phone number of your pharmacy or the address of where to send the prescription if it is mail ordered.
- The date of your child's next appointment in the Pediatric Neurology Clinic.
- Your name, daytime and early evening phone numbers, and when you can be reached.

The Pediatric Neurology Clinic is located in the Physician Office Center, 2nd floor, Pediatrics.

Driving Directions

From I-68

Take exit 7, Pierpont Road, turn west onto WV RT 857. At the 2nd traffic light, turn south onto US RT 119. You will drive up a steep hill and come to a traffic light; the Morgantown Airport will be on your left. Continue through the light to the 2nd light (approx. 1 mile) and turn right onto RT 705. Go to the 2nd light on RT 705, turn left onto Don Nehlen Drive. Turn right at the next light. The signs will direct you to the booth where you will get a parking pass.

From I-79

Take exit 155, Star City. A sign at the end of the exit ramp will direct you toward West Virginia University. At the 2nd traffic light at the bottom of the hill, bear to the right onto US RT 19. Cross the Star City Bridge and go straight through the next light up the hill to the 2nd light on US RT 19. Turn left onto Patterson Drive. Get in the right lane as soon as possible. Proceed on Patterson Drive through 2 traffic lights. Just prior to the 3rd traffic light, you will bear right onto Elmer Prince Drive. Follow the signs for Robert C. Byrd HSC/WVU. Continue in the right lane to POC/RUBY Hospital and the WV Eye Institute. The signs will direct you to the booth where you will get a parking pass.

Introduction

Epilepsy is a term that refers to an individual who experiences recurrent seizures. About 400,000 American children under the age of 18 have epilepsy. It affects children at different ages and in different ways.

For some, it will be easily controlled with medication and outgrown after a few years. For others, it may be a lifelong challenge affecting many areas of life.

Epilepsy is not contagious. Epilepsy is not a mental illness. Epilepsy is not mental retardation.

We are pleased to introduce this informational resource guide, which was developed through funding from the US Health Resources and Services Administration and the National Epilepsy Foundation. The guide was designed to reduce the stigma associated with epilepsy by increasing awareness about the condition and to improve access to services and support for children and youth with epilepsy. It is our hope that this guide will become a valuable resource to which you are comfortable referring in order to meet your everyday needs in the home, school and workplace, as well as in a host of other settings throughout the community.

What Is Epilepsy?

2

Epilepsy is a disorder of the brain.

A child's brain contains billions of nerve cells. They talk with each other through tiny electrical charges that fire on and off in random fashion. When some or all of these cells suddenly begin to fire together, a wave of electrical energy sweeps through the brain, causing a seizure.

Seizures interfere with the brain's normal functions. They can cause a child to have sudden changes in consciousness, movement or sensation.

Having a single seizure does not mean a child has epilepsy – epilepsy is the name for seizures that happen more than once without a known, treatable cause such as fever or low blood sugar.

For 70% of people with epilepsy, the cause is unknown.

For the remaining 30%, common, identifiable causes include head injury, infections that affect the brain (encephalitis or meningitis), abnormal brain development, brain tumor or genetic factors.

I. Partial Seizures

Partial seizures are also called ***focal seizures*** and are the most common type of seizure experienced by people with epilepsy. This type of seizure affects just one part of the brain, and the symptoms will vary with the part of the brain involved. It can stimulate your emotions and your senses, make your body move in ways you can't control and interfere with perceptions.

A.) Simple Partial Seizures

During *simple partial seizures*, you remain awake and alert throughout; however, you may not be able to speak or move until after the seizure is over. These types of seizures can affect movement, emotion, sensations and feelings in unusual and sometimes even frightening ways. Usually you can remember exactly what happened during the seizure.

Uncontrolled movements can occur in just about any part of the body; eyes may move from side to side; blinking, unusual movements of the tongue or twitching of the face also may occur. Some simple partial seizures can start with the shaking of a hand or foot, which then spreads to the arm or leg or even the whole side of the body.

Some people experience a sudden feeling of fear or a feeling that something unpleasant is about to happen. They may also experience *déjà vu* or a feeling that they have "been there before."

Simple partial seizures can produce sensations such as unpleasant tastes, strange smells (also usually unpleasant) or nausea. People may hear hissing, buzzing or ringing sounds or voices that are not really there.

B.) Complex Partial Seizures

Complex partial seizures, which used to be called **Temporal lobe or Psychomotor Seizures,** affect a larger area of the brain. Although your eyes may stay open and you may move around, you will probably be unconscious, almost in a trancelike state. You will not be able to control how you move or what you say and do.

Usually a complex partial seizure starts with a blank stare and loss of contact with surroundings. This is often followed with chewing movements of the mouth, picking at or fumbling with clothing, mumbling and performing simple, unorganized movements over and over again.

During the seizure, you may be able to speak, but the words are unlikely to make sense and you will not be able to respond to others in an appropriate way. You may repeat the same phrase over and over again. At times, partial seizures can evolve into generalized tonic-clonic seizures.

After the seizure has stopped, you will have no memory of what has taken place.

II. Generalized Seizures

Generalized seizures affect both sides of the brain at the same time. You will experience a loss of consciousness, often for a short period of time, but sometimes for much longer.

A.) Absence Seizures

Absence seizures, also called **Petit Mal seizures**, can happen so quickly that they sometimes can go unnoticed. There is no warning sign. You experience a sudden but fleeting loss of awareness, sometimes accompanied by staring. There is no warning or **aura** and no aftereffect. They usually last only a few seconds.

B.) Atonic Seizures

Atonic seizures, also known as **Drop Attacks**, produce an abrupt loss of muscle tone. Your head may fall to your chest; your legs may buckle; and you may have a loss of posture or sudden collapse. Because they are so abrupt, without warning, atonic seizures can result in injuries to the head and face**.**

C.) Myoclonic Seizures

Myoclonic seizures are rapid, brief contractions of bodily muscles that occur at the same time on both sides of the body. Occasionally they involve one arm or foot. People usually think of them as sudden jerks or clumsiness.

D.) Tonic-Clonic Seizures

Tonic-Clonic seizures, also known as **Grand Mal seizures or a Convulsion**, are the most common and best known type of generalized seizure. They begin with a stiffening of the limbs (the tonic phase) followed by a jerking of the limbs and face (the clonic phase).

During the tonic phase, breathing may slow down or even pause, causing cyanosis (blueing) of the lips, nail beds and face. Breathing typically returns during the clonic (jerking) phase, but it may be irregular. The clonic phase usually lasts less than a minute.

Tonic-clonic seizures occur in different ways. Some people experience only the tonic, or stiffening, phase, while others will experience only the clonic or jerking movements.

Incontinence may occur as a result of the seizure. The tongue or inside of the mouth may be bitten during the episode. Breathing afterward may be noisy and appear to be labored. **Nothing should be placed in the mouth during the seizure; you cannot "swallow your tongue"** as some myths insist. Turning the person to one side will help prevent choking and keep the airway clear.

Following the seizure, the person will be lethargic, possibly confused, and will want to sleep. Headache sometimes occurs. Full recovery takes minutes to hours, depending on the individual.

Seizure Syndromes

An epilepsy syndrome is a cluster of signs and symptoms that may occur together in an individual with epilepsy, such as seizure type, age of onset, cause, electroencephalograph (EEG) patterns, course, response to therapy and prognosis. Identification of an epilepsy syndrome may allow your doctor to make more specific treatment decisions based on the syndrome. Approximately 15% to 25% of children with epilepsy may be identified as having a syndrome.

Benign Rolandic Epilepsy

Benign Rolandic Epilepsy is the most common epilepsy syndrome in childhood. It is called *benign* because nearly all children will outgrow it during puberty and *rolandic* because this is the area in the brain where the seizure starts. It is classified as a partial seizure because only one part of the brain is involved. It affects nearly 25% of all children who have epilepsy, and it usually starts between the ages of 3 and 12 years.

A typical event usually occurs as the child is waking up in the morning. It involves twitching, numbness or a tingling of the face or tongue (a partial seizure), which can cause speech to be unclear and difficult to understand. It may also produce drooling. These seizures usually last no longer than 1 to 2 minutes. The child remains fully awake.

Sometimes the child will also have tonic-clonic seizures, usually occurring during sleep. This is a generalized seizure, where the child will lose consciousness; he or she will become stiff and then have regular jerking movements of the arms and legs.

Childhood Absence Epilepsy

Children with *Childhood Absence Epilepsy* have seizures that appear as staring spells. The child is not aware or responsive. Each episode lasts only about 10 seconds. The child's eyes may roll up briefly. These seizures can occur up to 50 times a day. Often the child is not even aware that anything has happened and resumes the activity he or she was doing.

These types of seizures usually begin between the ages of 4 and 8 years, and they usually disappear by midadolescence. Rarely, these children may have a generalized tonic-clonic seizure.

Juvenile Myoclonic Epilepsy

Juvenile Myoclonic Epilepsy (JME) most often appears during puberty. This syndrome is characterized by myoclonic seizures, sudden jerks of the arms, shoulder or occasionally the legs. These seizures usually occur in the early morning, soon after awakening. However, parents usually seek medical attention following a generalized tonic-clonic seizure. Occasionally children or teens may also have absence seizures.

This type of seizure is more likely to occur in children who have family members with generalized epilepsy. People with JME usually do not outgrow the disorder and will need to continue on medications for many years – in some cases for the rest of their lives.

Infantile Spasms

An *infantile spasm* is a specific type of seizure syndrome occurring early in life, typically between 3 and 6 months of age. It is also known as ***West Syndrome.*** It is uncommon, affecting only one baby out of a few thousand.

The typical pattern for infantile spasms consists of a sudden jerk followed by stiffening. Often the arms are flung out as the knees are pulled up and the body bends forward. Each seizure lasts only a second or two, but they can occur close together in a series of 2 to 100 spasms at a time. Sometimes the spasms are mistaken for colic.

Infantile spasms occur most often just after the child is waking up. They rarely occur during sleep.

Treatment is usually steroid therapy with a drug known as adrenocorticotropic hormone (ACTH). Many of these children have associated developmental delay and may, as they grow older, develop other types of seizures. Generally, the sooner the diagnosis and seizures are controlled, the better the outcome.

The Diagnosis

The doctor's main tool in diagnosing epilepsy is a **careful medical history** with as much information as possible about the seizure. Questions like the ones below will be asked:

When was the first time your child had a seizure or staring spell?

When was your child's last seizure?

How long did it last?

Recall what happened and describe the seizure like a movie, scene by scene — before the seizure, during the seizure and after the seizure.

Does anyone in the family have seizures?

The doctor will also perform a thorough physical examination, especially of the nervous system.

Another diagnostic tool is an **electroencephalograph (EEG).** This is a test that records brain waves that are picked up by tiny wires taped to the head. Electrical signals from brain cells are recorded as wavy lines by the machine. Brain waves during or between seizures may show special patterns, which help the doctor decide whether or not someone has epilepsy or whether to start treatment.

Imaging methods, such as **computerized tomography (CT) or magnetic resonance imaging (MRI)** scans, may be used to search for any growths, scars or other physical conditions in the brain that may be causing the seizures.

Which tests and how many of them are ordered may vary, depending on how much each test reveals.

Medication

Children often take the same **antiepileptic** medicines as adults do. Medication may be prescribed as tablets, sprinkles, capsules or a syrup.

These drugs are designed to prevent seizures. Whenever possible, doctors try to control seizures with one drug. This is known as **monotherapy.** Some children, however, may have to take more than one drug, **polytherapy.**

Children may respond so well to medication that no further seizures occur as long as the medication is taken regularly and an effective **blood level,** in the child, is maintained.

Not having seizures does not mean that the medication is no longer needed. Most children require a minimum of several years of therapy. **Always ask the doctor before stopping antiepileptic medication.** Giving a child only part of the medication or stopping it abruptly can cause a serious increase in seizure activity.

The goal of treatment is to achieve the greatest level of control and the lowest level of side effects at the lowest possible dose. The search for the best medication for any individual child, at times, can be quick and easy or, at times, may require trying several medications over a long period of time.

Common side effects from antiepileptic drugs include fatigue, nausea, changes in vision, and weight gain or weight loss. The side effects depend on the medication and response of your child. Not all children experience side effects.

Some side effects are linked to high dosages. Others are due to individual sensitivity or allergic reaction. Some tend to happen when a new medication is started, but they go away (or become less of a problem) as the child becomes accustomed to the medication.

Helping the Medicine Work

- Ask your doctor about possible side effects associated with the medicine and what you should do if you see them.
- 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 make the next appointment then.
- Don't change the dose or discontinue seizure medicine on your own without checking with your child's doctor.
- Ask for refills from your pharmacy several days before the medication is due to run out.
- Ask your doctor whether any over-the-counter medicines may interfere with the epilepsy drug your child is taking. Check with the pharmacist when buying other medicines.
- 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 of medication.

Surgery

If medicines do not control a child's seizures, he or she may be a candidate for surgery.

The most common form of epilepsy surgery removes a fairly small area of the brain where seizures begin. Sometimes, larger areas are removed.

Other surgery performed less often blocks nerve pathways in the brain to stop the spread of seizures from one part of the brain to another.

Ketogenic Diet

If medications fail to control a child's seizures, your doctor may recommend a special high fat, low carbohydrate, restricted calorie diet. It is called a **ketogenic diet.**

Calories are strictly limited, and parents have to be very careful not to allow the child to eat anything — even cookie crumbs or toothpaste — that isn't on the diet or hasn't been premeasured and preweighed within the formula.

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

> WARNING: The ketogenic diet is serious medicine. It is not a do-it-yourself diet. It could have serious effects if not monitored by a physician and dietitian.

Vagus Nerve Stimulation (VNS)

Vagus nerve stimulation is a new type of treatment that may be tried when seizures cannot be controlled by other methods.

The stimulator is a surgically implanted device, about the size of a stop watch, that delivers small electrical stimulation bursts every few minutes to the vagus nerve.

Data collected regarding the use of a VNS implant showed that up to two-thirds of patients see improvement with this treatment method.

Recognizing Seizure Triggers

1. Failure to take medication as prescribed
2. Lack of sleep
3. Illness or fever
4. Alcohol (excessive use or withdrawal)
5. Poor nutrition or dehydration
6. Drug abuse
7. Trauma
8. Stress
9. Flickering light patterns
10. Menstrual cycle

For Nonconvulsive Seizures

You don't have to do anything if a person has brief periods of staring or shaking of the limbs. If someone has this kind of seizure, one that produces a dazed state and automatic behavior, the best thing to do is:

- Watch the person carefully and explain to others what is happening.
- Speak quietly and calmly in a friendly way.
- Guide the person gently away from any danger. Block hazards such as stairs, roads or hot stoves.

Stay with the person until full consciousness returns.

For Convulsive Seizures

- Protect the child from injury while the seizure continues, but don't forcefully hold them down.
- Whenever possible, try to lay the child on a soft surface and turn the child on one side.
- Place something flat and soft under the head, loosen tight neckwear and remove eyeglasses.
- Do not place anything in the mouth.
- Cardiopulmonary resuscitation (CPR) should not be given during a seizure.
- Time the seizure with your watch.
- As the jerking slows down, make sure breathing is unobstructed and is returning to normal.
- Do not try to give medicine or fluids until the child is fully awake and aware.
- Reassure the child and gently help to reorient him or her as consciousness returns.

Emergency Aid

Unless your doctor tells you otherwise, a seizure in a child with known epilepsy that ends after a couple of minutes does not usually require a trip to the emergency room.

You should call 911:

- If the seizure lasts longer than 5 minutes and shows no signs of slowing down.
- If you have given Diastat (rectal diazepam) and the seizure doesn't stop within 5 minutes.
- If your child has one seizure after another without waking up.
- If the child appears bluish gray after the seizure is over or seems to have trouble breathing after the seizure is over.
- If the seizure is due to an injury.
- If the seizure occurred in water and the child may have aspirated water into the lungs.
- If your child might be pregnant.

It may be helpful to talk with your other children about epilepsy and encourage them to ask you questions about it. Children often have misconceptions and may even blame themselves in some way about what has happened to a brother or sister. They may be afraid they will start to have seizures, too.

Siblings may also feel abandoned and lonely because the parents have been so focused on the problems of the child with epilepsy. Parents may have had to spend long hours at the hospital while the other children waited at home.

Setting aside some special time for the other children in the family and making time to answer their questions fully should help.

Discipline

Parents often worry that discipline or emotional upset because of a wish that is not being granted will cause a seizure. They may be tempted to give in to unreasonable demands from a child with epilepsy because of that natural concern. However, ignoring behavior you don't like (so long as no one is likely to get hurt by it) and rewarding good behavior is as likely to work for children with epilepsy as it is for other children.

If this is something that happens in your family, ask your doctor about the level of risk for your child and how you can exert discipline in a way that is safe and reasonable.

Informing Relatives

Informed, understanding relatives are a wonderful source of strength when a child has epilepsy.

Others may have mistaken beliefs about this condition that hail from an earlier time. They may think it is somehow linked to mental illness (it isn't), or is someone's fault (wrong), or is related to mental retardation (usually not), or is even a sign of spiritual possession (an old myth that still lingers).

Helping other family members understand the true nature of epilepsy as a medical condition affecting brain function will set these fears at rest.

Building Self-Esteem

One of the biggest challenges for parents when a child has seizures is to help the child maintain self-esteem.

Studies comparing children with epilepsy with children who have other chronic health conditions, such as asthma or diabetes, show that having seizures has a more negative effect on how children feel about themselves.

The way parents feel about the epilepsy also affects how the child feels.

Families that are open and accepting and that help the child build on strengths can make a positive difference in the child's life.

How Parents Can Help

- Emphasize the positive; praise success.
- Build on things the child likes and can do.
- Avoid describing the child's seizures or the financial burden of medical care as problems in front of the child.
- Encourage a special hobby or lessons to acquire a special skill.
- Discuss seizures and epilepsy openly with the child and answer his or her questions about it.
- Encourage the child to be active and to have as much social contact with other children as possible.
- Try not to make your child's seizures a reason not to do things the family would otherwise do.
- Take some time for yourself and your other children without feeling guilty about it.

Avoiding Overprotection

A major problem for children with epilepsy is the well-meaning efforts of adults to protect them from harm.

Parents may limit a child's participation in the usual childhood activities because of fear that a seizure will occur during the activity or that exertion will somehow trigger a seizure.

This is unfortunate for several reasons. First, vigorous physical activity is not generally associated with a greater number of seizures; in fact, studies suggest fewer seizures will occur when the average child is active.

Second, the child is excluded from experiences that would help him or her develop social skills and self-confidence. The sense of being different, of being unable to join what others are doing, encourages dependence in the child and keeps him socially immature.

The school experience offers the child with epilepsy a unique opportunity to break this pattern of overprotection and isolation. Wherever possible, he or she should be encouraged to take part in all school activities.

Safety

The following tips are ways parents can help improve safety for children with epilepsy:

- A monitor in the child's bedroom may alert you to the sound of a typical seizure.
- Avoid top bunks. A lower bunk, a regular bed, a futon or even a mattress on the floor is a safer place to sleep for a child with seizures.
- A well-fitting helmet with a face guard may protect against head and facial injuries from severe drop seizures.
- Have the child wear a life vest when near water, including the backyard pool.
- Closely supervise showers and tub baths. Older children and teenagers should be encouraged to take only showers.
- Put a list of first aid steps on the refrigerator or some other place where it's easy to find.
- When you have babysitters, go over first aid steps, write down the phone number where you or a relative can be reached, and include the doctor's number and the one for the emergency squad on the same sheet.
- If your child is going to sleep at a friend's or relative's house overnight, make sure a copy of the list goes along, too, and that an adult in the house knows what to expect and what to do if a seizure happens.
- Not every childhood injury is preventable, whether or not a child has seizures. Try to strike a balance between safety and overprotection.

Having seizures at school can be socially damaging to a child and frightening to others. However, it doesn't have to be.

A well-informed, confident teacher and a supportive school nurse and school administration can make all the difference in the world.

There are several steps parents can take to create a more accepting school environment for a child.

Parent and Teacher Communication

When good communications exist between parents and teachers, the teacher can feel comfortable asking questions that will help the teacher do his or her best for the child. These questions may include the following:

- What kind of seizures does the child have?
- What do they look like?
- How often does he or she have them?
- How long do they usually last?
- What should the teacher do when the child is having a seizure?
- Is medicine going to be given or taken at school?
- What arrangements have been made for medication?
- What has been the child's previous experience with epilepsy at school?

If the child is having very infrequent seizures or has complete seizure control, this kind of basic information may be all that is needed.

However, if the seizures are frequent, the teacher will want to discuss with the parents how they should be handled, how he or she plans to explain the condition to the other children, whether there are any learning disabilities, and whether the child has an understanding of his disorder and would feel comfortable answering questions that the other children might have. If the child is old enough and the parents agree, he or she could be part of the discussion.

School Performance

Most children with epilepsy test in the average intelligence quotient (IQ) range and will keep up with the class. However, research studies have shown that a number of youngsters with this condition achieve at a lower level than their test scores would predict.

There may be several reasons why this happens:

- The medicines that prevent seizures may be affecting the child's ability to learn. If the child seems excessively sleepy and lacks energy, the parents should be told. A change in medicine or the times it is taken might help.
- Unrecognized seizure activity in the brain may be interfering with attention. Difficulty paying attention is a frequent problem for children with epilepsy, particularly boys. Anxiety over the possibility of having a seizure may be affecting attention as well.
- There may be some underlying condition in the brain that is interfering with learning, memory or the way the brain handles information. These problems may show up in math, reading and tasks involving memory.
- A child may be showing the educational effects of prolonged periods away from school for medical tests and treatment. He or she may also have missed important aspects of previous instruction because of an undiagnosed seizure disorder.

Missed schooling may be the easiest problem to remedy, since it can be approached through tutoring and remedial work. The other problems are more subtle and may require special techniques to identify and overcome.

For example, testing by a neuropsychologist or school psychologist who is knowledgeable about epilepsy can help determine if the difficulties a child is having are due to some specific learning disability. Once identified, special education techniques may help the youngster overcome the problem.

It is important to remember that these are problems that occur only in some children with epilepsy. Many children with epilepsy do well in school without any of these difficulties.

Special Planning

Some children with epilepsy will need specialized planning, with goals and objectives carefully spelled out, developed in partnership between the parent and the school.

School activities should be open to all children, including children with seizures.

Various federal laws (Section 504 of the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act [IDEA] and the Americans with Disabilities Act) and state laws protect children with disabilities from discrimination on the basis of disability.

Elementary and Secondary Education and Federal Law

While most children with epilepsy can participate with the other students in the classroom, some may require additional services, such as being allowed to take medication during school hours. Federal law, as well as many state laws, grants children with epilepsy the right to receive those supplemental services and if necessary, special education. These federal laws are known as the Individuals with Disabilities Education Act and Section 504 of the Rehabilitation Act of 1973. Every state has laws providing some kind of educational services for children with disabilities.

IDEA and Your Right to a "Free, Appropriate Education"

IDEA, formerly known as the Education for All Handicapped Children Act (P.L. 92-142), guarantees children with disabilities a "free, appropriate public education in the least restrictive setting." This means that local school districts must develop and pay for an educational program that is tailored to the individual needs of the child with a disability. In some situations, the local school district may even be legally required to pay tuition at a private school or the cost of an outside provider if it is unable to provide the needed services in its own schools.

To qualify for protection under IDEA, a child must have a disability that adversely affects his or her ability to learn, and thus needs special education and related services. "Special education" includes instruction that is specifically designed to meet the child's unique needs that result from a disability. It can involve adapting the content, methodology or delivery of the instruction. Disabilities covered under IDEA may include health impairments such as epilepsy, as well as traumatic brain injuries, learning disabilities, mental retardation and autism. (A child with epilepsy or another disability who does not qualify for services under IDEA may, however, qualify for services under Section 504 of the Rehabilitation Act, as discussed below.)

By law, public schools are required to educate children with disabilities in the "least restrictive environment" possible. This means schools cannot place a child with epilepsy in a special education classroom, away from students who do not have a disability,

simply because the child with the disability requires special services. Instead, the school must allow these children to be mainstreamed and provide the related service in some other way, such as having the child visit the nurse at a designated time each day to receive medication.

For a child with epilepsy, commonly requested related services include: health services (such as administration of medication in the event of a prolonged seizure), specialized recreation services (for a child with uncontrolled seizures), counseling (to compensate for the social adjustment aspects of epilepsy) and other non-instructional services. Specialized instruction may also be necessary to compensate for accompanying learning disabilities or other cognitive impairments resulting from frequent losses of consciousness or other impairment of attention or learning ability. In some situations, it may be appropriate for the child to receive this instruction once a week for an hour at a time, for example, whereas in other situations, the severity of a child's disability requires he or she receive specialized instruction full time. Under IDEA, the school is required to provide effective educational services in the least restrictive environment, including any related services that may be necessary to educate the child.

By law, school personnel, parents, and when possible, the child, must work together to identify the child's educational and related-service needs and to develop a plan to ensure that these needs are met effectively and in the least restrictive environment possible. This process is called the Individualized Education Plan (IEP). Any child between 3 years old and 21 years old has the right to be evaluated at least once every three years to determine if he or she needs to develop an IEP. (Some states have similar requirements for children under 3 years old. For information about these state programs, ask your child's pediatrician or contact the local board of education.) If an IEP is required, by law it must be put in writing and reviewed on a yearly basis. It is important to list all needed services since schools are not required to provide services that are not listed. Parents and students have a right to participate in the meeting, which must be scheduled at a mutually convenient time for all participants.

If you believe your request for an IEP has been unfairly denied, the IEP developed does not fit your child's needs, or you have another concern about the IEP process, and are unable to resolve the dispute with school personnel, you may request mediation, request a due process hearing, or file a complaint with your state's education agency. (A due process hearing involves an impartial third party, called a hearing officer, who hears the evidence about a dispute and issues an opinion regarding the requirements of IDEA.) For more information about requesting mediation in your state, visit the Consortium for Appropriate Dispute Resolution in Special Education (CADRE Caucus) website, http://www.directionservice.org/cadre/state/. For additional information about IDEA, visit the U.S. Department of Education's Office of Special Education Programs Web site at http://www.ed.gov/about/offices/list/osers/osep/index.html. Also, for a Web site which provides an overview of IDEA and a discussion of advocacy strategies, see http://www.fape.org/idea/index.htm

Section 504 and Your Right to Be Free From Discrimination

Section 504 prohibits schools that receive federal funding from discriminating against a child because of disability in academic and nonacademic activities, such as school field trips and extracurricular activities. The law also requires schools to provide a child who is otherwise qualified to participate in the particular activity a reasonable accommodation. A reasonable accommodation is a modification in a program or policy, or an auxiliary aid that enables an individual with a disability to participate in a program. Depending upon the child's needs and the activity involved, a reasonable accommodation may include administering medicine at a particular time in accordance with a doctor's directions, waiving a requirement that all children be able to swim in order to attend a general recreational program, or allowing the child to attend the program on a reduced schedule.

Your child is only entitled to a reasonable accommodation under Section 504 if he or she has a disability as the law defines it. This means he or she must have an impairment that substantially limits one or more major life activities. Examples of major life activities include caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing or learning. If your child needs a reasonable accommodation, you should request that the school develop a Section 504 Plan. If your child qualifies for both Section 504 and IDEA, you can address both needs in the IEP alone.

If you believe your child's rights under Section 504 have been violated, you may file a complaint with your regional Office of Civil Rights of the U.S Department of Education or sue in federal court. Information on filing a Section 504 complaint and the electronic form can be found at http://www.ed.gov/about/offices/list/ocr/complaintintro.html. Alternatively, you may call (800) 421-3481, (TDD) (877) 521-2172. For particularly helpful and detailed guidance from the Department of Education on Section 504, see "Frequently Asked Questions About Section 504 and the Education of Children with Disabilities," which is available at http://www.ed.gov/about/offices/list/ocr/504faq.html. To locate your regional Office of Civil Rights, visit http://bcol01.ed.gov/CFAPPS/OCR/contactus.cfm.

Where Can I Find Help?

The Families and Advocates Partnerships for Education works to improve the educational outcomes for children with disabilities. It links families, advocates, and self-advocates to information about IDEA. To contact the organization, go to http://www.fape.org, call (952) 838-9000, (952) 838-0190 TTY, or request information by writing to PACER Center, PACER Center, 8161 Normandale Boulevard, Minneapolis, MN 55437-1044. Additionally, assistance is available from the parent training and information centers (see www.taalliance.org/centers/index.htm). Each state has at least on such center, which assists families obtain appropriate education and services for their children with disabilities; trains and informs parents and professionals on a variety of topics; resolves problems between families and schools or other agencies; and connects children with disabilities to community resources that address their needs.

For information on obtaining a referral to an attorney in your area that may be able to provide specific advice or representation, please visit the Web site for the Jeanne A. Carpenter Epilepsy Legal Defense Fund, at www.epilepsylegal.org, or call our Consumer Information Services Division toll free at 1-800-EFA-1000 (1-800-332-1000). For general legal information about this and discrimination issues, please visit our Web site at http://www.epilepsyfoundation.org/answerplace/Legal, or call our Consumer Information Services Division.

Tips for Attending Your Child's Individual Education Program (IEP) Conference

- Either you or your child's school may initiate a conference. The time arranged should be convenient for both you and the school staff.
- Look over any information you already have about your child. Do you have any questions? Is there something you don't understand? Write down any questions and bring them to the meeting.
- List your child's strengths and weaknesses and any concerns you have about his or her current educational program.
- You have the right to see any records that pertain to your child at school and can request copies of them.
- You can bring someone with you to the IEP meeting. This can be a spouse, friend, relative or educational advocate.
- At the IEP meeting, ask questions and expect answers from the school staff. Use this opportunity to give school personnel your insights about your child, whom you know better than anyone else.
- If you don't understand something, ask that it be explained. The program is being developed for your child based on his or her needs as determined by strengths and weakness, special problems and learning needs. If you don't agree with something, let the team know. Changes can be made if you state your ideas and reasons.
- When you feel teachers and other staff are doing a good job, let them know it. Communication should be open and occur often.
- Your child's progress must be reviewed each year at a new IEP meeting, and a new IEP must be developed for the following school year.
- Remember, you have the right to request a new IEP meeting anytime you feel your child's educational needs are not being met. When you have questions or concerns, talk to your child's teacher or principal. School staff can help you decide if the IEP team needs to be brought together again to discuss your child and make any changes needed.

QUESTIONNAIRE FOR PARENT OF A STUDENT WITH SEIZURES

Please complete all questions. This information is essential for the school nurse and school staff in determining your student's special needs and providing a positive and supportive learning environment. If you have any questions about how to complete this form, please contact your child's school nurse.

CONTACT INFORMATION:

Student's Name:_____ School Year:_____ Date of Birth:_____

School:_____ Grade:_____ Classroom:_____

Parent's/Guardian's Name:_____ Tel. (H):_____
Tel. (W):_____ Tel. (C):_____

Other Emergency Contact:_____ Tel. (H):_____
Tel. (W):_____ Tel. (C):_____

Student's Neurologist:_____ Tel:_____ Location:_____

Student's Primary Care Dr.:_____ Tel:_____ Location:_____

Significant medical history or conditions:_____

SEIZURE INFORMATION:

1. When was your child diagnosed with seizures or epilepsy?_____
2. Seizure type(s):

Seizure Type	Length	Frequency	Description

3. What might trigger a seizure in your child?_____

_____

4. Are there any warnings and/or behavior changes before the seizure occurs? YES NO
   If YES, please explain:_____

_____

5. When was your child's last seizure?_____
6. Has there been any recent change in your child's seizure patterns? YES NO
   If YES, please explain:_____

_____

7. How does your child react after a seizure is over?_____

_____

8. How do other illnesses affect your child's seizure control?_____

_____

_____

BASIC FIRST AID: Care and Comfort Measures

9. What basic first aid procedures should be taken when your child has a seizure in school?

_____

_____

_____

_____

_____

_____

_____

Basic Seizure First Aid:

- Stay calm and track time
- Keep student safe
- Do not restrain
- Do not put anything in mouth
- Stay with student until fully conscious
- Record seizure in log

For tonic-clonic (grand mal) seizure:

- Protect head
- Keep airway open/watch breathing
- Turn student on side

10. Will your child need to leave the classroom after a seizure? YES NO

If YES, what process would you recommend for returning your child to classroom?_____

_____

SEIZURE EMERGENCIES:

11. Please describe what constitutes an emergency for your child? (Answer may require consultation with the treating physician and school nurse.)

_____

_____

_____

_____

_____

_____

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 diabetic
- Student has breathing difficulties
- Student has a seizure in water

12. Has your child ever been hospitalized for continuous seizures? YES NO

If YES, please explain: _____

_____

SEIZURE MEDICATION AND TREATMENT INFORMATION:

13. What medication(s) does your child take?

Medication	Date Started	Dosage	Frequency and time of day taken	Possible side effects

14. What emergency/rescue medications are prescribed for your child?

Medication	Dosage	Administration Instructions (timing* & method**)	Insructions After Administration:

* After 2nd or 3rd seizure, for cluster of seizure, etc. ** Orally, under tongue, rectally, etc.

15. What medication(s) will your child need to take during school hours?_____

_____

16. Should any of these medications be administered in a special way? YES NO
If YES, please explain:_____

_____

17. Should any particular reaction be watched for? YES NO
If YES, please explain:_____

_____

18. What should be done when your child misses a dose?_____

_____

19. Should the school have backup medication available to give your child for a missed dose? YES NO
20. Do you wish to be called before backup medication is given for a missed dose? YES NO
21. Does your child have a Vagus Nerve Stimulator (VNS)? YES NO
If YES, please describe instructions for appropriate magnet use:_____

_____

SPECIAL CONSIDERATIONS AND PRECAUTIONS:

22. Check all that apply and describe any considerations or precautions that should be taken.

❒ General health:_____ ❒ Physical functioning:_____
❒ Learning:_____ ❒ Behavior:_____
❒ Mood/coping:_____ ❒ Physical education (gym)/sports:_____
❒ Recess:_____ ❒ Field trips:_____
❒ Bus transportation:_____ ❒ Other:_____

GENERAL COMMUNICATION ISSUES:

23. What is the best way for us to communicate with you about your child's seizure(s)?

_____

_____

_____

24. Can this information be shared with the classroom teacher(s) and other appropriate school personnel? YES NO

Parent's/Guardian's Signature:_____Date:_____Dates Updated:_____

Seizure Observation Record

Student's Name				
Date & Time				
Seizure Length				
Preseizure Observation (briefly list behaviors, triggering events, activities)				
Conscious (yes/no/altered)				
Injuries (briefly describe)				
Muscle Tone/Body Movements	Rigid/clenching			
	Limp			
	Falling down			
	Rocking			
	Wandering around			
	Whole body jerking			
Extremity Movements	(R) arm jerking			
	(L) arm jerking			
	(R) leg jerking			
	(L) leg jerking			
	Random movement			
Color	Bluish			
	Pale			
	Flushed			
Eyes	Pupils dilated			
	Turned (R or L)			
	Rolled up			
	Staring or blinking (clarify)			
	Closed			
Mouth	Salivating			
	Chewing			
	Lip smacking			
Verbal Sounds (gagging, talking, throat clearing, etc.)				
Breathing (normal, labored, stopped, noisy, etc.)				
Incontinent (urine or feces)				
Postseizure Observation	Confused			
	Sleepy/tired			
	Headache			
	Speech slurring			
	Other			
Length to Orientation				
Parents Notified? (time of call)				
EMS Called? (call time & arrival time)				
Observer's Name				

SEIZURE ACTION PLAN

Effective Date_____

THIS STUDENT IS BEING TREATED FOR A SEIZURE DISORDER. THE INFORMATION BELOW SHOULD ASSIST YOU IF A SEIZURE OCCURS DURING SCHOOL HOURS.

Student's Name:_____ Date of Birth:_____

Parent/Guardian:_____ Phone:_____
Cell:_____

Treating Physician:_____ Phone:_____

Significant Medical History:_____

_____

SEIZURE INFORMATION:

Seizure Type	Length	Frequency	Description

Seizure triggers or warning signs:_____

Student's reaction to seizure:_____

BASIC FIRST AID, CARE & COMFORT:

(Please describe basic first aid procedures.)

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

Basic Seizure First Aid:

- Stay calm and track time
- Keep student safe
- Do not restrain
- Do not put anything in mouth
- Stay with student until fully conscious
- Record seizure in log

For tonic-clonic (grand mal) seizure:

- Protect head
- Keep airway open/watch breathing
- Turn student on side

Does student need to leave the classroom after a seizure? YES NO

If YES, describe the process for returning the student to the classroom:_____

_____

_____

_____

EMERGENCY RESPONSE:

A "seizure emergency" for this student is defined as:

_____

_____

_____

_____

_____

_____

_____

_____

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 diabetic
- Student has breathing difficulties
- Student has a seizure in water

Seizure Emergency Protocol: (Check all that apply and clarify below.)

❒ Contact school nurse at _____

❒ Call 911 for transport to _____

❒ Notify parent or emergency contact _____

❒ Notify doctor _____

❒ Administer emergency medications as indicated below _____

_____

❒ Other_____

_____

_____

TREATMENT PROTOCOL DURING SCHOOL HOURS:

(Include daily and emergency medications.)

Daily Medication	Dosage & Time of Day Given	Common Side Effects & Special Instructions

Emergency/rescue medication:_____

Does the student have a Vagus Nerve Stimulator (VNS)? YES NO

If YES, describe magnet use:_____

SPECIAL CONSIDERATIONS AND SAFETY PRECAUTIONS:

(Regarding school activities, sports, trips, etc.)

Physician's Signature:_____ Date:_____

Parent's/Guardian's Signature:_____ Date:_____

Children and youths with epilepsy can participate in most all sports and physical activities; in fact, it is encouraged. Participation helps promote physical and mental well-being, promotes positive self-esteem, and encourages social interaction with their peers and self-expression in the child.

Studies have shown that children and adults with epilepsy actually feel better and have better seizure control when they maintain a regular exercise program.

Children should be encouraged to participate in all school activities. To exclude them is to discriminate and promote social isolation.

Activities With No or Very Little Risk, Where No Extra Supervision Is Required:

Aerobics … Badminton ... Baseball (with helmet) … Bowling … Cross-Country-Skiing … Dancing … Field Hockey (with helmet) … Jogging … Hiking … Golf … Most Track and Field Events … Ping Pong …Soccer … Softball (with helmet)

Activities With Moderate Risk, May Need Supervision or Help During a Seizure:

Archery … Basketball … Bicycling (with helmet) … Canoeing (with life vest) … Diving (not high dive) … Downhill Skiing (with helmet …Fishing … Football (with helmet) … Horseback riding (with helmet) … Hockey (with helmet) … Hunting … Ice Skating (with helmet) … Lacrosse (with helmet) … Roller Blading and Skating (with helmet) … Sledding (with helmet) … Tennis … Swimming … Volleyball … Wrestling

Activities With High Risk That Should Be Avoided:

Boxing … Bungee Jumping … Hang Gliding … Full Contact Karate … Mountain Climbing … Rock Climbing … Sky Diving … Surfing ... Scuba Diving … Water Skiing

Some Important Tips for Sports Participation:

- Before your child tries a new sport, discuss it with your child's epilepsy treatment provider, especially if the sport is of moderate or high risk.
- Inform a the coach and, if appropriate, a teammate or friend about your child's condition, and ensure they know what to do in case of a seizure.
- Many sports require a helmet; this is especially important when your child has epilepsy because a head injury can trigger or aggravate seizures.
- Have your child follow all safety regulations for the sport.
- For higher risk sports, make sure that someone else (coach, lifeguard, teammate or friend) is watching and can help your child if necessary. Be sure that person knows about your child's condition and knows what to do in case of a seizure.
- Never swim alone … this goes for everybody.
- Life jackets are a good idea for all water activities.

Driving With Epilepsy

7

Every state has different driving laws. When you apply for a license, some states may require that your doctor send a letter to the Department of Motor Vehicles stating that you have been seizure-free, and in his or her opinion, you therefore can drive safely if you meet your state's other driving requirements.

State	Seizure-Free Period	Periodic Medical Updates Required After Licensure	Doctors Must Report Epilepsy	DMV Appeal of License Denial
Maryland	Varies with each individual case (no fixed time limit)	At discretion of Motor Vehicles Administration	No	Yes, within 15 days
Ohio	None	Every 6 months or 1 year until seizure –free 5 years	No	Yes, within 30 days
Pennsylvania	6 months, with exceptions	At discretion of medical advisory board	Yes	Yes
West Virginia	1 year, with exceptions	At discretion of medical advisory board	No	Yes, within 10 days

Tips for Safer Driving With Epilepsy:

- Always take epilepsy medicine every day on time.
- If your medicine has been changed, ask your doctor about driving. Don't drive until you know how the change makes you feel.
- Don't drive if you're very tired or have been going without sleep.
- Don't drink alcohol if you're going to drive. That's good advice for everyone.
- If you have epilepsy, alcohol may make you have a seizure.
- Follow the licensing rules in your state.
- Report all seizures to your doctor.
- Realize there will be times when you have to ask someone for a ride.
- Do not drive if you start having seizures after getting your license.

Medication Information

Date Started	Date Stopped	Medication	Dose & How Given	Times Given	Prescribed by Whom	Reaction

Allergies:_____

_____

Emergency Room and Hospitalization Record

Name:_____DOB:_____

Date	Location	Problem	Cause of Problem	Test Done

Health Conditions/Allergies

Name:_____DOB:_____

Date Began	Date Ended	Description

Medical Expenses Information

Date	Provider	Cost	Insurance Paid	Parent Owes	Date Paid

Emergency Information Form for Children With Special Needs

	Date form completed	Revised	Initials
	By whom	Revised	Initials

Name:	Nickname:	Birth Date:
Home Address:	Emergency Contact Names:	
Parent/Guardian:	Emergency Contact Relationship:	
Home/Work Phone:	Home/Work Phone:	
Signature/Consent*:	Primary Language:	

Physicians

Primary Care Physician:	Emergency Phone:
	Fax:
Current Specialty Physician:	Emergency Phone:
Specialty:	Fax:
Current Specialty Physician:	Emergency Phone:
Specialty:	Fax:
Anticipated Primary ED:	Pharmacy:
Anticipated Tertiary Care Center:	

Diagnoses/Past Procedures/Physical Exam:

1.

2.

3.

4.

Synopsis:

Baseline physical findings:

Baseline vital signs:

Baseline neurological status:

*Consent for release of this form to health care providers

Diagnoses/Past Procedures/Physical Exam (continued):	
Medications:	Significant Baseline Ancillary Findings (lab, x-ray, ECG):
1.	
2.	
3.	
4.	Prostheses/Appliances/Advanced Technology Devices:
5.	
6.	

Management Data:	
Allergies (medications/foods to be avoided)	and why:
1.	
2.	
3.	
Procedures to be avoided:	and why:
1.	
2.	
3.	

Immunizations (mm/yy)												
Dates						Dates						
DPT						Hep B						
OPV						Varicella						
MMR						TB status						
HIB						Other						

Antibiotic prophylaxis: Indication: Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements:		
Problem:	Suggested Diagnostic Studies:	Treatment Considerations:

Comments on Child, Family, or Other Specific Medical Issues	
Physician/Provider Signature:	Print Name:

Dear Parents,

As a parent of a young lady with special needs including epilepsy, I truly know what it's like to battle this sometimes-frightening disease. Because the treatment of epilepsy often presents children and families with numerous challenges, we have compiled a resource list to help you navigate the confusing system of services.

As part of this list, we have included state, regional, and national resources. For children who are diagnosed with epilepsy, there are educational, financial, and support services that many families may be unaware of. We hope this packet will assist you in finding the resources you need to make life easier for you and your child with special needs.

Should you have specific questions about the packet, please feel free to contact me. I can be reached at the number below and my email contact is also listed for your convenience.

Sincerely,

Carrie Cobun, BA
Parent Educator
Klingberg Center for Child Development

(304) 293-2890

ccobun@hsc.wvu.edu

State Health/Medical Resources

Office of Maternal Child and Family Health Systems Point of Entry
Division of Infant, Child and Adolescent Health

350 Capitol Street, Rm 427
Charleston, WV 25301
304-558-5388 or toll free (in WV) 800-642-9704 or 800-642-8522 for more information or to make a referral
www.wvdhhr.org/spe/

The Children with Special Health Care Needs' "Systems Point of Entry" (SPE) unit assists families of children with special health care needs to look at options and find links to the appropriate systems to meet their specific needs and to access benefits/entitlements. The family's and child's needs are assessed, and referrals are made to health and social service programs both in and out of the Office of Maternal, Child and Family Health (OMCFH).

West Virginia 211

112 Adams Street, Rm. 205
Fairmont, WV 26554

Dial 2-1-1 toll free from any telephone and most cellular phones to find health and social services available in West Virginia. Calls are answered 24 hours a day, 7 days a week.

State CHIP Program

Health care for low-income uninsured children
WV CHIP
877-982-2447
www.wvchip.org

HealthCheck

350 Capitol Street, Rm. 427
Charleston, WV 25301
Toll free (in WV) 800-642-9704
www.wvdhhr.org/mcfh/ICAH/healthcheck/

For children from birth through 20 years of age who have active Medicaid cards. Services provided include health check-ups, dental/hearing/vision services, lab tests, immunizations, treatment for health problems discovered during the exams, referrals to medical specialists and health education. The program is free for eligible participants.

Dental Care Clinic

304-598-5100

Located in Monongalia County, this clinic serves children to age 21 from all over WV. Services include education, exams, cleaning, fluoride treatments, etc. This clinic accepts both the WV Medical Card and the WV CHIP card.

Feeding and Swallowing Clinic

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd., Morgantown, WV 26505
304-293-4692
www.cedwvu.org

This clinic provides interdisciplinary assessments for infants, children and youths who may have feeding, eating and/or swallowing problems. The assessment is completed by an interdisciplinary team, which includes professionals in the areas of nutrition, occupational therapy, behavioral psychology, speech-language pathology and social work.

Adolescent Health Initiative

304-558-5722 or toll free (in WV) 800-642-8522

Seeks to improve the health of youths ages 10 to 17 by educating them about the causes of preventable health problems and the ways to avoid them.

The W.G. Klingberg Center for Child Development

Robert C. Byrd Health Sciences Center, West Virginia University
Physicians Office Center (POC), Pediatric Suite, Morgantown, WV 26506
304-293-7331 or toll free 800-842-3627, ask for Klingberg Center
www.hsc.wvu.edu/klingberg/

Provides diagnostic and follow-up services in an Early Childhood Clinic and an Attention Deficit Disorder Clinic. The Early Childhood Clinic serves children from birth through age 5 and addresses problems such as autism and related disorders, developmental delays (including speech delays), discipline, feeding and mealtime problems, infant/toddler behavior difficulties, sleep problems, multiple disabilities, and consultation with early intervention programs. The Attention Deficit Disorder clinic focuses on providing diagnostic and follow-up services to children ages 6 to 12 who are displaying attention problems. The Klingberg Center publishes a free quarterly magazine, *The Parent Connection*, for families who have children with special needs and professionals who work with children.

Leadership Education in Neurodevelopmental Disabilities (LEND) Clinic

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd., Morgantown, WV 26505
304-293-4692 or toll free 877-724-8244
lrisk@hsc.wvu.edu
www.cedwvu.org/programs/neuro/

An interdisciplinary team consisting of a behavioral psychologist, occupational therapist, speech pathologist, audiologist, social worker, pediatric neurologist and other providers as needed, evaluate children from birth to age 21 who have developmental or behavior problems. The team provides recommendations for services, offers follow-up behavioral treatment when appropriate and gives specific advice as to further testing or consultations. WV Mental Health Representative for Children and Youth

WV Mental Health Representative for Children and Youth

Division of Children's Mental Health Services, DHHR
350 Capitol St., Rm. 350
Charleston, WV 25301-3702
304-558-0627

Coordinator of Vocational Education for Students with Disabilities

Division of Technical & Adult Education
WV Dept. of Education
1900 Kanawha Blvd.
Bldg. 6, Rm., 230
East, Charleston, WV 25305
304-558-2349

The Friday Clinic

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd., Morgantown, WV 26505
304-293-4692 or toll free 877-724-8244
www.cedwvu.org/programs/friday/

The Friday Clinic is an integrated physical education program serving over 218 special education students in Monongalia County with same-age peers without disabilities. It provides developmentally appropriate health-related fitness and motor skill acquisition opportunities for children and adolescents with special needs through aquatics, movement education, sport, and fitness and wellness activities.

Assistive Technology Clinic

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd., Morgantown, WV 26505
304-293-4692 or toll free 877-724-8244
ced@hsc.wvu.edu
www.cedwvu.org/programs/atclinic/

The Assistive Technology (AT) Assessment Clinic provides comprehensive assistive technology evaluations and follow-up management for individuals with multiple disabilities who can use assistive technology to support their independence and enhance their quality of life. The assessment process includes on-site pre-assessment home/school/worksite visits, followed by in-house clinical assessments. Additionally, a limited number of tele-assessments (AT-TV), using video conferencing technology, are provided for individuals without easy access to the CED clinics in Morgantown.

Traumatic Brain Injury Cognitive Clinic

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd., Morgantown, WV 26505
304-293-4692 or toll free 877-724-8244
ced@hsc.wvu.edu
www.cedwvu.org/programs/tbi/clinic.html

The Traumatic Brain Injury Cognitive Clinic provides neuropsychological screening and assessments for individuals of all ages who have sustained a traumatic brain injury. The clinic is conducted by a licensed neuropsychologist and technical staff. Referrals come from state agencies, service providers, family members and the Brain Injury Association of West Virginia.

Developmental Disabilities Assessment and Treatment Clinic

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd., Morgantown, WV 26505
304-293-4692 or toll free 877-724-8244
ced@hsc.wvu.edu
www.cedwvu.org/programs/ddclinic/

The Developmental Disabilities Clinic provides a wide range of assessment and treatment options for children with developmental disabilities that are necessary for improved growth and development. These may include behavioral assessments and strategies for improving children's social, cognitive and communication skills. Referrals may come from parents, schools, agencies and physicians.

Insurance/Funding

Children with Disabilities Community Service Program (formerly TEFRA)

304-558-1711

The WV Children with Disabilities Community Service Program allows states to provide Medicaid to children with disabilities who live at home and are under 18 years of age. States that have this program must provide Medicaid coverage to all children who qualify. Services are not based on family income.

Partnership for Prescription Assistance

www.pparx.org/Intro.php

This website has a link to all of the free health care clinics in West Virginia along with instructions on how someone can get help with their prescription costs.

***Helping Patients with Medication Cost* by Angela Y. Baker, MSW**

Pleasant Valley Hospital
2520 Valley Drive, Point Pleasant, WV 25550
304-675-4340 ext. 4407

This is a manual that provides information about patient assistance programs, pharmaceutical discount cards, special offers by drug companies, and state, civic and community programs to assist individuals in making needed medications affordable.

Education

West Virginia Department of Education, Office of Special Education

Dr. Lynn Boyer, Executive Director
1900 Kanawha Blvd., E., Rm. 304
Charleston, WV 25305
304-558-2696 or toll free 800-642-8541 (Voice/TDD)
wvde.state.wv.us/ose/

This office administers special education programs, services and resources and supports agencies in their efforts to provide services and programs to meet current and future needs of special education students.

State Coordinator for NCLB (No Child Left Behind)

West Virginia Department of Education
1900 Kanawha Boulevard East
Charleston, WV 25305
304-558-2699
wvachieves.k12.wv.us/

Programs for Infants and Toddlers With Disabilities Under Part C of IDEA: Ages Birth to 3

Pamela Roush, Director
West Virginia Birth to Three
Office of Maternal, Child and Family Health
Bureau of Public Health
350 Capitol Street, Rm. 427
Charleston, WV 25301
304-558-5388, 800-642-9704
pamroush@wvdhhr.org
www.wvdhhr.org/birth23

Head Start/Early Head Start

304-558-4638, ask for Head Start/Early Head Start

Infants, toddlers and children who meet the national poverty guidelines are eligible for these programs. Head Start/Early Head Start covers a wide range of child development services. These services include educational, health, social and related services (parent involvement, medical, dental, mental health, occupational therapy, physical therapy, speech therapy, assistive technology).

Programs for Children With Disabilities: Ages 3 to 5

Ginger Huffman, Coordinator, Preschool Disabilities
Office of Special Education, Bldg. 6, Rm. 304
1900 Kanawha Blvd., E.
Charleston, WV 25301
304-558-2696, 304-558-0400 or toll free 800-642-8541
vhuffman@access.k12.wv.us

This office administers preschool programs for children ages 3 to 5 in the public school system throughout WV.

Cooperative School Program (CSP)

800-642-8207

The Cooperative School Program is an agreement between the Division of Rehabilitation Services (DRS) and the Board of Education to see that students with disabilities are provided all the rights they are entitled to by law. It enables DRS and the schools to work together to provide the best services available to eligible students age 16 and older. The DRS counselor will assist students in their transition from school to adult life.

Parent-Educator Resource Center

Betsy Peterson, Parent Coordinator
West Virginia Parent-Educator Resource Center (PERC) Project
West Virginia Department of Education
Office of Special Education
1900 Kanawha Boulevard E, Building 6, Rm. 304
Charleston, WV 25305-0330
304-558-2696
bpeterso@access.k12.wv.us
wvde.state.wv.us

Higher Education Policy Commission

1018 Kanawha Blvd., East, Suite 700,
Charleston, WV 25301
304-558-2101
www.hepc.wvnet.edu

The commission produced *Services for Students with Disabilities: A Helping Hand,* a booklet which lists public colleges (2- and 4-year) in West Virginia and the types of accommodations that these colleges indicate are provided for their students who have disabilities.

Learning Disabilities

Jennifer Carriger, President
Learning Disabilities Association of West Virginia
908 Highland Road
Charleston, WV 25302
866-985-3211
jcarriger@citynet.net
www.wvlda.org

Coordinator for Transition Services

Karen Ruddle, Coordinator
Office of Special Education
West Virginia Department of Education
1900 Kanawha Boulevard East
Building 6, Rm. 243
Charleston, WV 25305-0330
304-558-3075
kruddle@access.k12.wv.us
wvde.state.wv.us/ose/

Transition to Employment and Adult Life

WV Division of Rehabilitation Services (DRS)

P.O. Box 50890
State Capitol Complex
Charleston, WV 26305
800-642-8207
www.wvdrs.org

The West Virginia Division of Rehabilitation Services (DRS) is an agency of the state government that helps West Virginians who are disabled achieve independence within the workplace, family and local community.

West Virginia Work Incentives Planning and Asistance Project (WIPA)

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd.
Morgantown, WV 26505
304-293-4692
www.cedwvu.org/programs/wipa/

This program provides information to people with disabilities who receive Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) benefits and would like to work. Benefits specialists, working from geographically strategic locations around WV, will answer questions about work choices, Medicaid cards and benefits.

Medicaid Work Incentive Network (M-WIN)

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd.
Morgantown, WV 26505
304-293-4692
www.cedwvu.org/programs/mwin/

The mission of the Medicaid Work Incentive Network (M-WIN) is to remove barriers to employment for persons with disabilities by creating health systems change through the Medicaid program. The M-WIN project will work in full partnership with state agencies, local service providers, community organizations and persons with disabilities.

Transportation

Perdidos, Inc.

105 Valley View Drive
Beckley, WV 25801
866-WVA-RIDE (1-866-982-7433), all volunteers—leave message
www.perdidosinc.org

This is a specialized database that covers the entire state. It provides linkage to services for transport to medical facilities, mental health and drug rehabilitation programs, welfare-to-work programs, after-school programs, foster care, homeless shelters and general transportation for everyday needs in connection with many state agencies and nonprofit organizations.

West Virginia Department of Transportation

Division of Public Transit
Building 5, Rm. A-830
1900 Kanawha Boulevard, East
Charleston, WV 25305-0432
304-558-0428
304-558-0174 (fax)
info@dot.state.wv.us

The Division of Public Transit is the state administering agency for all federal and state programs relating to public transportation.

Potomac Valley Transit Authority (PVTA)

Non-Emergency Medical and Public Transportation
Grant County Industrial Park
P.O. Box 278
Petersburg, WV 26847
304-257-1414 or 800-565-7240

PVTA serves Grant, Hardy, Pendleton, Hampshire and Mineral Counties. Non-Emergency Medical will transport patients to doctor's offices and hospitals in Charlottesville, VA; Harrisonburg, VA; Morgantown, WV; Cumberland, MD and all local hospitals and doctor's offices. For best service call at least 3 days in advance.

Family Support

Epilepsy Foundation of WV

800-707-0997
info@wvepilepsy.org
www.epilepsyfoundation.org/local/westvirginia

Parent Network Specialist Program

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd.
Morgantown, WV 26505
304-293-4692 or toll free 877-724-8244
www.cedwvu.org/programs/pns/

The Parent Network is a statewide system of Parent Network Specialists (PNS) who serve as resource mentors to parents of children with special needs. PNS assist parents in locating services and information that may benefit their children. For more information, contact the Parent Network Specialist who serves your area or call Mary Ellen Zeppuhar, Ed D, Program Manager, at 304-293-4692, ext. 1108.

WV Developmental Disabilities Council (DDC)

304-558-0416
304-558-2376 (TDD)
110 Stockton Street
Charleston, WV 25312-2521
www.wvddc.org

The council's mission is to assure that West Virginians with developmental disabilities receive the services and support they need to exercise self-determination and achieve independence, productivity and inclusion in their communities.

Bureau for Behavioral Health and Health Facilities—DHHR

Office of Behavioral Health Services (OBHS)
350 Capitol Street, Rm. 350
Charleston, WV 25301
304-558-0627
www.wvdhhr.org/obhs/dd.htm

The bureau offers family support, crisis services and community case management. It provides support and assistance in accessing community mental health and substance abuse treatment.

Medicaid Title XIX MR/DD Waiver Program

350 Capitol Street, Rm. 350
Charleston, WV 25301
www.wvdhhr.org/bhhf/mrddwaiver/default.asp
304-558-3628 or 304-558-0627

This program provides reimbursement for services to instruct/train, support and assist persons who have mental retardation and/or related conditions to achieve the highest level of independence and self-sufficiency.

WV Family Support Program

Division of Developmental Disabilities
350 Capitol Street, Rm. 350
Charleston WV 25301
304-558-0627
www.wvdhhr.org/bhhf

This division serves families who have someone living at home who has a developmental disability. This includes both natural and foster families. Services provided include respite care, home modifications, assistive technology, etc. Family Support Program coordinators are located throughout the state.

WV Parent Training and Information (WVPTI)

Pat Haberbosch, Project Director
1701 Hamill Ave.
Clarksburg, WV 26301
phaberbosch@aol.com
304-624-1436 or 800-281-1436 in WV
wvpti@aol.com
www.wvpti.org

This project provides information to parents and professionals who work with children with disabilities on the following topics: IEPs, state and federal laws, transition, negotiations and strategies, inclusion and early intervention/preschool. WVPTI has regional trainers, all of whom are parents of special needs children located across WV.

WV Specialized Family Care Program (SFCP)

Patricia Snyder Nisbet, Program Manager
350 Capitol Street, Rm. 691
Charleston, WV 25301
304-558-0074
patsnydernisbet@wvdhhr.org
Kathern Casto, Program Assistant
304-558-0969
katherncasto@wvdhhr.org

This program, administered by the Center for Excellence in Disabilities, is a statewide placement and family support system designed to serve the needs of children and adults with developmental disabilities.

Positive Behavior Support Crisis Services

Center for Excellence in Disabilities (CED)
Mark Clingan, Supervisor
Morgantown, WV
304-293-4692, ext. 1112
Kathy Torsney, Crisis Specialist
Morgantown, WV
304-293-4692, ext. 1166
Carol Newlon, Crisis Specialist
Big Chimney, WV
304-720-3200, ext. 202

The Crisis Services Project works with agencies that support individuals who have developmental disabilities and who are in a behavioral crisis.

The Family Resource Center

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd.
Morgantown, WV 26505
304-293-4692, ext. 1102

Open Monday through Friday from 9:00 a.m. to 5:00 p.m., this program provides a lending library for families, teachers, therapists, other professionals, students with disabilities and others. It features books, videos, curricula, etc., on a variety of disability-related topics.

West Virginia Assistive Technology System (WVATS) Bulletin Board

Center for Excellence in Disabilities (CED)
West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Rd.
Morgantown, WV 26505
304-293-4692
www.cedwvu.org/programs/wvats/virtuallibrary.html

Comprehensive assistive technology assessments are available for adults, children and youth through the Assistive Technology Assessment Clinic (AT Clinic) at the Center for Excellence in Disabilities (CED). Assessments are overseen by a nationally certified Assistive Technology Practitioner and designed to help individuals identify and use assistive technology to support independence and enhance quality of life.

Advocacy

WV Advocates

Litton Bldg. – 4th Floor
1207 Quarrier St.
Charleston, WV 25301
304-346-0847 or toll free 800-950-5250
WVAinfo@wvadvocates.org
www.wvadvocates.org

WVA Advocates provide free advocacy to individuals with disabilities. The website provides resources for assistive technology and funding information via the Internet.

WV EMS-TSN, Inc.

304-965-0573

It provides free Hartley/Medley advocacy to individuals with disabilities.

Americans with Disabilities for Attendant Programs Today (ADAPT)

ADAPT of West Virginia
Ken Ervin
304-594-3644
adaptwv@hotmail.com

ADAPT is a national organization, founded in 1977, working for the civil rights of persons with disabilities. West Virginians with disabilities have formed a group that is prepared to take the initiative and action necessary to bring to the attention of legislators, media and the general public issues of importance to persons with disabilities.

Coalition for West Virginia's Children

P.O. Box 1925
Charleston, WV 25327
304-342-6972 or toll free: 800-883-5190
cwvc@coalitionwvchildren.org

The Coalition for West Virginia's Children is a group of individuals and organizations dedicated to improving the well-being of our state's children and families through education, collaboration and advocacy.

Miscellaneous

Center for Excellence in Disabilities (CED)

West Virginia University
Robert C. Byrd Health Sciences Center
959 Hartman Run Road
Morgantown, WV 26505
304-293-4692
304-293-7294 (fax)
www.cedwvu.org

Statewide resources for agencies, organizations, people with disabilities and their families to provide training, technical assistances, service, product development and research.

West Virginia CHADD (Children and Adults with Attention Deficit/Hyperactivity Disorder)

Lea Burnside, Coordinator
P.O. Box 154
Duck, WV 25063
304-364-5305
leab@citynet.net
www.wvchadd.org

This is a statewide branch of a national organization that works to improve the lives of people with AD/HD through collaboration, advocacy, research, education and support.

Brain Injury Association of West Virginia, Inc.

P.O. Box 574
Institute, WV 25112
304-766-4892 or toll free (in WV) 800-356-6443
BIAWV@aol.com

Learning Disabilities Association of West Virginia

Lora Fulton, President
908 Highland Road
Charleston, WV 25302
888-985-3211
wvlda@hotmail.com
www.namiwv.org
NAMIWV@aol.com

West Virginia Speech-Language-Hearing Association

Brian K. Reed, President
2103 36th Street
Parkersburg, WV 26101
breed1975@aol.com

National

www.epilepsyfoundation.org

www.epilepsy.com/

www.paceusa.org/

cureepilepsy.org/

nichcy.org/states.htm

www.naecepilepsy.org/

www.ibe-epilepsy.org/about_mem_chapt.asp

www.ilae.org/ or
www.ilae.org/Visitors/Chapters/Index.cfm

www.epilepsyfoundation.org/drsearch.cfm

www.aesnet.org/

www.pacer.org

cshcn.org

www.medicalhomeimprovement.org

www.eparent.com

www.familyvoices.org

www.aucd.org

www.supportpath.com

www.cms.hhs.gov/medicaid/waivers/waivermap.asp

www.aap.org/

absence seizure - (formerly called petit mal) generalized seizure most commonly seen in children; characterized by a lapse in consciousness with a blank stare that begins and ends within a few seconds. May be accompanied by eye blinking or subtle automatisms. Individuals usually quickly return to their baseline.

adjunctive therapy - (syn.: add-on therapy) treatment administered in addition to another therapy, as when one medication is taken with another.

AED (antiepileptic drug) - a seizure-preventing drug.

American Epilepsy Society (AES) - Founded 1946. The American Epilepsy Society is one of the oldest neurological professional organizations in the United States. The Society seeks to promote interdisciplinary communication, scientific investigation and exchange of clinical information about epilepsy. The Society holds an annual meeting with educational symposia for all types of epilepsy professionals. Membership consists of professional workers in epilepsy or closely related fields who have expressed interest in the objectives of the Society, including clinicians, scientists investigating basic and clinical aspects of epilepsy, nurses, social workers, psychologists and other professionals. www.aesnet.org

amygdala - an almond-shaped structure in the brain, in the temporal lobe adjacent to the hippocampal head, which is part of the limbic system. The amygdala is especially involved in the regulation of affect and emotion.

aneurysm - bulge in a blood vessel caused by a weakness in the vessel wall; sometimes a cause of seizures when it occurs in the brain.

Angelman syndrome - a genetic disorder marked by mental retardation, incoordination, poor speech development, unprovoked laughter and, in 80% of affected children, seizures, which usually begin in the first 3 years of life. Associated with abnormalities on chromosome 15.

anticonvulsant - preventing or arresting convulsions; an agent that prevents convulsions.

antiepileptic - preventing seizures; there is no agent that prevents epilepsy (i.e., there is no antiepileptogenic drug).

aphasia - inability to produce or understand speech. Occasionally seen during or following partial complex or generalized tonic-clonic seizures.

apnea (sleep apnea) - temporary halts in breathing often followed by gasping for air; may be caused by airway obstruction (obstructive apnea) or insufficient respiratory drive (central apnea). May be associated with disturbed sleep or daytime sleepiness.

ataxia - difficulty coordinating muscle movement or balance.

atonic seizure - (syn.: drop attack) a brief generalized seizure where sudden complete loss of muscle tone results in collapse. May be preceded by myoclonic jerks.

aura - a sensation recognized by a patient caused by a partial simple seizure. May include uneasiness, déjà vu, sensory illusions (odors, visual illusions or misconceptions, sounds), stomach discomfort, dizziness. May progress to a partial complex seizure with loss of consciousness.

automatism - repetitive, stereotyped, undirected, purposeless actions not consciously controlled; automatisms occur most commonly in partial complex seizures. May include chewing, fumbling with clothes, blinking, etc.

autonomic seizure - seizures characterized by predominately autonomic symptoms such as nausea, fever, tachycardia, headache or stomachache.

blood level monitoring - measurement of levels of antiepileptic drugs in the bloodstream, which may be helpful in optimizing the dose of medication or in confirming compliance. Most commonly used for the "older" AEDs—Phenobarbital, Dilantin (phenytoin), Tegretol (carbamazepine), Depakote (valproic acid) and Zarontin (ethosuximide).

bioavailability - the amount of a drug taken orally or intravenously that will reach the bloodstream and then be available to provide the intended effect.

bioequivalency - equal performance of two or more substances used as therapy.

breakthrough seizures - seizures that occur despite attempted therapy.

CAT scan (computerized axial tomography) - (syn.: CT scan) a radiological technique that produces images of the brain that show brain structure.

catamenial (catamenial seizures) - an exacerbation of seizures related to hormonal changes during a woman's menstrual cycle.

cavernous angioma - an abnormal tangle of blood vessels; sometimes causes seizures when it occurs in the brain.

cerebellum - a brain structure involved in the control and coordination of voluntary muscle movements.

chronic - affecting a person for a long period of time.

clonic - a seizure involving muscle contractions and relaxations.

clustering - a tendency in some individuals with epilepsy for their seizures to occur in groups (clusters) with repeated seizures that follow immediately upon one another or which happen within hours of each other followed by periods without seizure activity.

cognition - the process by which knowledge is acquired; awareness, thinking, learning and memory.

complex partial seizure - a partial seizure associated with impaired or lost consciousness. Features of the seizure will vary with the part of the brain from which the seizure arises. Usually associated with automatisms and followed by a postictal state before returning to baseline.

compliance - the accuracy with which a patient follows prescribed medication or treatment schedules and instructions. Compliance can be enhanced by careful instruction and education and by treatment schedules that are simplified and fit into the patient's lifestyle.

convulsion - involuntary muscle contractions most commonly seen in generalized tonic-clonic seizures.

corpus callosotomy - severing/cutting of the corpus callosum, the most important fiber tract connecting the two sides of the brain in order to interrupt the spread of seizures from one side of the brain to the other. *(See "surgery for epilepsy.")*

cortex (cerebral cortex) - the surface layer (gray matter) of the cerebral and cerebellar hemispheres. Many seizures arise from the cortex of the cerebral hemispheres.

cortical dysplasia - abnormal development of the cortex, a condition that may be associated with seizures.

craniotomy - an opening made into the skull for epilepsy surgery or other types of brain surgery.

cryptogenic - has a suspected but unknown cause. *(See "idiopathic.")*

depth electrodes - thin wires placed in the brain to detect seizure activity.

diurnal seizures - seizures that occur routinely in relation to day/night cycles.

EEG (electroencephalograph) - apparatus that records, in the form of brain waves, electrical activity of the brain through electrodes attached to the scalp. May detect abnormal brain activity that may be associated with seizures but must always be correlated with the clinical history.

encephalitis - inflammation of the brain mostly commonly from an infection or as the result of other diseases; sometimes causes seizures.

epilepsy - a condition in which an individual experiences recurrent seizures. Estimated to affect 3 million Americans.

Epilepsy Foundation - founded 1967 as the Epilepsy Foundation of America. National office is in Landover, MD. The voluntary nonprofit organization that provides local and national services for people with epilepsy and funds research into causes and cures for the disorder.

epileptologist - a physician, typically a neurologist, who has specialized training and expertise in the diagnosis and treatment of epilepsy.

etiology - the cause of a disease or medical condition.

febrile seizure - a seizure related to high fever in infants and children usually under age 5. Most children who have febrile seizures do not develop epilepsy.

focal seizure - an epileptic seizure that involves one hemisphere of the brain; a partial seizure.

focus - area of the brain where seizure activity begins.

frontal lobe - located in front of the head, behind the forehead; frontal lobe controls decision-making, novel problem solving, planning, and motor movement. *(See also "lobe," "parietal lobe," "temporal lobe," "occipital lobe.")*

gamma knife surgery (radio surgery) - a form of radiation therapy that uses highly focused gamma rays to destroy seizure-causing tissue in the brain.

generalized seizure - an epileptic seizure that involves the whole brain. *(See types of generalized seizures: "tonic-clonic seizure" and "absence seizure.")*

grand mal - *(See "tonic-clonic seizure.")*

hippocampal sclerosis - cell loss and scarring (gliosis) of the hippocampus, a brain structure that lies in the temporal lobe and is a common site for the origin of partial complex seizures. Most common form is mesial temporal sclerosis (MTS).

hemispherectomy - the surgical removal of one hemisphere of the brain, performed almost exclusively in children for whom severely damaged tissue in one hemisphere produces uncontrollable seizures. *(See "surgery for epilepsy.")*

hippocampus - a region in the temporal lobe that is often the source of partial seizures; the hippocampus is part of the limbic system and closely associated with short-term memory function.

hyperventilation - a diagnostic method of rapid deep breathing performed to precipitate absence seizures or generalized discharges on an EEG. It is commonly performed with most EEG tests.

ictal - relating to or caused by an event or ictus such as a seizure or stroke; events surrounding a seizure are often identified as preictal (before the seizure), ictal (during the seizure) and postictal (after the seizure).

ictus - an event such as a seizure or a stroke.

idiopathic - has no known or even a suspected cause. *(See "cryptogenic.")*

incidence - the frequency with which new cases of a disorder occur over time; about 300,000 new cases of epilepsy occur in the United States each year. International incidence numbers are estimated at approximately 7.3 million new cases each year.

infantile spasms (West's syndrome) - an epilepsy syndrome that begins in the first years of life characterized by clusters of spasms (myoclonic jerks) often associated with developmental delay and an EEG that demonstrates a characteristic hypsarrhythmic pattern. May be treated with ACTH, steroids or antiepileptic drugs.

interictal the period of time between one seizure and another.

International Bureau for Epilepsy (IBE) - founded 1961. IBE is an international nongovernmental organization (NGO) that exists to improve the social condition and quality of life of all people with epilepsy and those who care for them. Through its worldwide network, IBE works to increase awareness, understanding and knowledge of epilepsy and to support its members to develop to their fullest potential. www.ibe-epilepsy.org/

international classification - developed by the International League Against Epilepsy, a periodically updated classification of seizure types, behaviors, and causes used to characterize seizure disorders and epileptic syndromes. Please see the International League Against Epilepsy's website for more information on international classification at www.ilae-epilepsy.org/Visitors/Centre/ctf/index.cfm.

International League Against Epilepsy (ILAE) - founded in 1909. Headquarters are in West Hartford, CT, and Brussels, Belgium. ILAE is the world's preeminent association of physicians and other health professionals working toward a world where no person's life is limited by epilepsy. Its mission is to provide the highest quality of care and well-being for those afflicted with the condition and other related seizure disorders. www.ilae.org/

intractable seizures - seizures that continue to occur despite treatment; refractory. Affects approximately 30% of people with epilepsy.

ketogenic diet - stringent, high fat, low carbohydrate diet that helps controls seizures in selected individuals, most commonly children.

Lafora disease - a rare form of myoclonic epilepsy leading to progressive disability and dementia.

Landau-Kleffner syndrome - an uncommon childhood epilepsy syndrome characterized by an epileptiform EEG that is maximal over the temporal regions and activated significantly by sleep, an acquired aphasia, cognitive and behavioral disturbances and seizures in 70% of affected children.

Lennox-Gastaut syndrome - a severe epilepsy syndrome beginning in early childhood characterized by an intractable mixed seizure disorder (myoclonic, absence, atonic and tonic-clonic seizures), an abnormal EEG and developmental delay that is often severe.

lesion - wound, injury or pathological process that results in a change in tissue (e.g., head injury which results in seizure-causing scars in the brain). Lesions are sometimes surgically removed to reduce or prevent recurring seizures.

limbic system - the limbic lobe and associated subcortical structures—amygdale, habenula, mamillary bodies, septal nuclei, hippocampus and portions of the thalamus, hypothalamus and midbrain. Often the site of or involved in partial seizure disorders.

lissencephaly - a disorder of brain development characterized by a smooth cerebral surface, abnormally thick and poorly formed cerebral cortex, and diffuse heterotopia. Often associated with seizures and severe developmental delay.

lobe - a major division of the cerebral hemispheres or cerebellum based on surface markings. (See "frontal lobe," "parietal lobe," "temporal lobe," and "occipital lobe.")

lobectomy - the surgical removal of all or part of the lobe of the brain bearing abnormal seizure-causing tissue (e.g., temporal lobectomy). (See "surgery for epilepsy.")

march - progression of muscular contractions from one muscle or muscle group to another.

MEG (magnetoencephalography) - records magnetic activity generated by the brain's electrical activity; helps identify brain areas where seizures begin or the site for functional activities (vision, sensory, language) within the brain.

meningitis - infection of the membranes of the brain and spinal cord most commonly caused by bacteria or viruses. May be associated with seizures.

mesial temporal sclerosis - *(See "hippocampal sclerosis.")*

monotherapy - use of a single antiepileptic drug for control of seizures.

mortality - death rate from a disorder over a period of time.

MRI (magnetic-resonance imaging) - a magnetic technique that provides three-dimensional images of brain structure. The most commonly used imaging technique to evaluate individuals with seizures.

multifocal epilepsy - epilepsy in which the seizures come from more than one location in the brain.

multiple subpial transection (MST) - surgery in which shallow cuts are made parallel to the surface of the cortex; used to reduce or eliminate seizures that come from critical brain areas that cannot be removed.

myoclonus - sudden, brief, shock-like contractions that may be generalized or confined to the face, trunk or one or more extremities. May represent seizures (myoclonic seizures) or in some cases be due to nonepileptic disorders or a normal physiological phenomenon such as hypnogogic myoclonus when falling asleep.

neurocysticercosis - a parasitic brain infection caused by the pork tapeworm; caused by eating undercooked infected pork; can cause seizures and seen more commonly in some U.S. immigrant populations.

neurologist - a physician with specialized training and expertise in the diagnosis and treatment of disorders of the brain and nervous system.

nocturnal seizures - seizures that occur routinely during sleep.

nonepileptic seizures - events that are determined not be epileptic (i.e., not resulting from an electrical discharge in the brain). They may be caused by physiological processes such as cardiac rhythm disturbances or hypoglycemia or a variety of psychological causes.

occipital lobe - the lobe at the rear of the brain that contains the visual cortex.

parietal lobe - the brain lobe that contains sensory cortex, sensory integration and language function.

partial seizure - a seizure arising from one part or location in the brain, categorized as either simple partial or complex partial. *(See "focal seizure.")*

perinatal - events that occur just before, during and in the days following birth.

PET (positron emission tomography) - function imaging of physiological functions and metabolism in the brain. May be helpful in the identification of a seizure focus.

petit mal - *(See "absence seizure.")*

pharmacotherapy - medication therapy.

photosensitivity - a reflex epilepsy in which seizures are triggered by flashing lights or patterns (e.g., strobe lights, video games or the flashing of a television screen). An estimated 5% of people with epilepsy have photosensitivity. This is routinely evaluated during an EEG with flashing lights. Not all individuals with photosensitivity have seizures.

polytherapy - (syn.: polypharmacy) the use of two or more antiepileptic medications for control of seizures.

postictal confusion - temporary incoherence, inability to respond appropriately or unfamiliarity with the environment that commonly follows partial complex and generalized tonic-clonic seizures.

prodromal warning - symptoms that precede a seizure by several hours or days (unlike an aura, which immediately precedes a seizure). Symptoms may include a feeling of nervousness, anxiety, uneasiness, dizziness or headache.

pseudoseizure - *(See "nonepileptic seizures.")*

reflex epilepsy - uncommon types of epilepsy that occur in response to specific sensory stimulus, including flickering light or patterns, sounds, tastes, smells, movements or sensations of touch.

refractory - resistant to treatment; intractable.

seizure - an event caused by an abnormal electrical discharge in the brain. Seizures can occur without any apparent cause (idiopathic) or can be related to a variety of other conditions and disorders such as brain injury, high fever, substance abuse, metabolic disorders or hypoglycemia, and they are not always a sign of epilepsy.

seizure prediction - a research and investigational tool for complex automated brainwave analysis that may predict an oncoming seizure before it is clinically apparent.

seizure semiology - the clinical symptoms and appearance of a seizure.

seizure threshold - the point at which a person can no longer tolerate a seizure-provoking stimulus, such as fever in a young child or high levels of alcohol in an adult, and a seizure occurs.

sharp waves, spikes and spike-wave discharges - types of brain wave activity seen on an EEG that may indicate a risk to have seizures. However, not all individuals with abnormal EEGs have seizures, and some individuals with epilepsy may have normal EEGs when performed between seizures.

simple partial seizure - a partial seizure in which consciousness is preserved during the seizure. Symptoms may include tonic-clonic activity in one part of the body and autonomic or sensory symptoms. The motor or sensory activity may progress to a partial complex or generalized convulsive seizure.

SPECT (single photon emission computed tomography) - a brain scanning device that helps locate the site of seizure activity through examination of the brain's blood flow.

status epilepticus - prolonged or recurrent seizures without recovery of consciousness between seizures. A medical emergency for which immediate medical assistance should be sought.

stereotactic surgery - brain surgery performed with the head held in an immoveable position by a special positioning device that allows the surgeon to precisely approach a region of the brain or lesion identified on prior neuroradiological studies.

subdural - referring to the area beneath the tough membrane (dura) that forms the outer envelope of the brain and the pia-arachnoid membranes that lie directly over the brain; subdural strips or grids are small plastic devices containing electrodes which are placed directly in this space to record brain wave activity as part of an epilepsy surgery evaluation to localize seizure activity.

SUDEP (sudden unexpected death in epilepsy) - a rare condition in which death occurs without an apparent cause but which is presumed to be related to the person's epilepsy.

surgery for epilepsy - surgical procedures to decrease seizure activity in individuals for whom medications and other treatments have been ineffective. These procedures include local resections, corpus callosotomy, multiple subpial transactions and hemispherectomy. Individuals referred for epilepsy surgery typically undergo a comprehensive evaluation to determine if they can be helped by a surgical procedure.

syncope - fainting due to a loss of blood flow to the brain; sometimes misdiagnosed as seizures.

syndrome - a set of symptoms characterizing a disease, disorder or condition. Epilepsy syndromes are defined by a number of features including the type of seizures, age of onset, course, response to therapy, prognosis, genetic inheritance and in some cases chromosomal findings.

temporal lobe seizure - a partial seizure arising from or involving the temporal lobe. Symptoms vary but may include visual and auditory hallucinations or distortions, déjà vu, feelings of detachment from surroundings and automatisms. Consciousness may be impaired or lost.

temporal lobe - a lobe of the brain that lies at the side of the head behind the temples, which is involved in hearing, memory, emotion and language. The temporal lobes are a common site for partial complex seizures. (See "lobe," "anterior lobe," "occipital lobe," "parietal lobe.")

teratogenic - a medication or treatment with the potential to cause birth defects.

Todd's paralysis - a transient focal neurological deficit following a seizure. Paralysis is the most common manifestation. Most often seen after partial motor seizures. The part of the body affected by Todd's paralysis usually reflects the area of the contralateral brain most intensely involved in the seizure. Symptoms usually resolve within minutes but can last up to 24 hours with full recovery to prior status.

tonic-clonic seizure - generalized seizures that usually begin with a sudden cry, fall and rigidity (tonic phase) followed by muscle jerks(clonic phase). May be associated with shallow breathing or temporarily suspended breathing and a change in skin color, possible loss of bladder or bowel control; the seizure usually lasts several minutes, followed by a confusion and fatigue.

transcranial magnetic stimulation - an investigative procedure that exposes the brain to a strong magnetic field as a potential treatment for epilepsy.

vagus nerve - a nerve that begins at the brain stem and passes into the neck to provide input to the throat, larynx, lungs, heart, esophagus, stomach and abdomen.

vagus nerve stimulator (VNS) - a device implanted in the chest wall and attached to the vagus nerve with a small electrode to reduce severity of seizures. Through stimulation of the vagus nerve, electrical impulses are sent at regular intervals to the brain.

video monitoring - simultaneous video (TV) monitoring and EEG recording of brain waves to help identify the type of seizure that is taking place and location of onset.

Wada test (intracarotid sodium amobarbital) - a test that helps locate speech and memory centers, named for creator Dr. Juhn A. Wada. An injection of amobarbital sedates one side or hemisphere of the brain. Doctors then check speech and memory function to determine which side is the dominant area for these crucial brain functions and if epilepsy surgery may be considered.

West's syndrome - *(See "infantile spasms.")*