

EPILEPSY



You and Your Child

Information for Parents



EPILEPSY FOUNDATION®
Not another moment lost to seizures™

This pamphlet is designed to provide general information about epilepsy to the public. It does not include medical advice. People with epilepsy should not make changes in treatment or activities based on this information without first consulting a physician.

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INTRODUCTION

About 300,000 American children under the age of 14 have epilepsy. It affects children at different ages, and in different ways.

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

The good news is that medical treatment of childhood epilepsy is getting better and research towards a cure continues.

More medications to control seizures are now available. New drugs are being tested in children and in adults. Some of them promise fewer side effects and are easier to take.

For children whose seizures are not controlled by medication or who experience unacceptable side-effects, other treatments may be tried. These include surgery, the ketogenic diet and vagus nerve stimulation (VNS).



WHAT IS EPILEPSY?

Epilepsy is a disorder of the brain.

A child's brain contains billions of nerve cells. They communicate with each other through tiny electrical charges. 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.

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

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.

CAUSES OF CHILDHOOD EPILEPSY

Pinpointing the cause of epilepsy is difficult at any age. In seven out of every ten cases, there is no known cause. These children are then said to have idiopathic epilepsy. “Idiopathic” is a Latin word meaning “of unknown cause.”

There are many possible causes of epilepsy in children, including: problems with brain development before birth; lack of oxygen during or following birth; a head injury that leaves a scar in the brain; unusual structures in the brain; tumors; a prolonged seizure with fever, or the after-effects of severe brain infections such as meningitis or encephalitis.



When a cause can be identified, children will be described as having symptomatic epilepsy. The seizures are thought to be a symptom of the underlying brain injury.

genetic factors

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Epilepsy is a common disorder. Frequently, more than one person within an extended family may have seizures.

In most cases, a clear pattern of inheritance of epilepsy within a family cannot be determined. However, there does seem to be a slightly increased risk among close relatives of people, with seizures, compared to risk in the general population.

It is therefore important to ask your relatives about a family history of seizures, and to share this information with your doctor.

Some disorders that may cause symptomatic epilepsy are genetically caused, and in some families there is a clear pattern of inheritance.



TYPES OF SEIZURES

Children with epilepsy, like adults, have seizures that can be divided into two broad groups: generalized seizures and partial seizures.

When the electrical disturbance involves the whole brain, the seizure is called generalized. When only part of the brain is affected, it is called partial. If the electrical disturbance starts in one part of the brain and then spreads, it is called a partial seizure secondarily generalized.

Some children have just one type of seizure, others have two or more.

generalized seizures

Generalized tonic clonic (grand mal)

Often called a convulsion, it starts with a sudden cry, fall, body stiffness followed by jerking movements as muscles tense, then relax, tense and relax. Breathing may be shallow or stop briefly. Skin may be bluish. There may be a possible loss of bladder or bowel control as muscles relax. It usually lasts a minute or two, after which normal breathing returns. The child may be confused or tired afterwards and fall into a deep sleep. He or she may complain of sore muscles or a bitten tongue.

Absence

It begins with a blank stare, beginning and ending abruptly and lasts only a few seconds, the seizures are often frequent. They may be

accompanied by rapid blinking, upward rolling of the eyes and chewing movements. Children may drop what they are holding. Children are out of touch during seizure, but they quickly return to full awareness once it stops. This type of seizure is often mistaken for daydreaming or inattention.

Atonic (also called drop attack)

A sudden loss of muscle tone makes the child collapse and fall. In some children all that happens is a sudden drop of the head. After a few seconds to a minute he or she recovers and regains consciousness. Drop attacks can cause injuries because of the force of the fall. Protective helmets may help, at least when the child is playing outside.

Myoclonic

These are sudden, brief, involuntary muscle jerks, a bit like the kind everyone has when a foot or leg suddenly jerks in bed. May be mild and affect only part of the body, or be strong enough to throw the child abruptly to the floor. May occur as a single seizure or a cluster of seizures.

partial seizures

Simple partial

These seizures affect movement, usually on one side of the body, but the child stays aware of his/her surroundings. They may cause jerking movements that start in fingers, toes, or other parts of the body, eventually affecting the entire side of the body. They may progress to a generalized convulsion. Partial seizures affecting sensations may cause things to look, sound, taste, smell or feel different. Effects can include stomach pain, nausea, a rising feeling in the stomach, or sudden fear or anger.

Complex partial

Consciousness is altered during these seizures; child won't know what he's or she's doing or where he or she is during the seizure. Often starts with bland stare, followed by chewing, followed by repeated movements that seem out of place and mechanical. The child may seem dazed and mumble. He or she may pick at clothes, pick up and put down objects, try to take clothes off or may run and appear afraid. The child may struggle or flail at restraint. The same pattern of actions may happen with each seizure. It lasts only a minute or two, but child may remain frightened and confused for longer time afterwards. There'll be no memory of what happened during the seizure.

Partial seizures can arise from any part of the brain. The symptoms that the child experiences will depend on the seizure location. Most complex partial seizures arise from the brain's temporal lobe and will have symptoms similar to those described above.

If the seizures are coming from the frontal lobe, they may produce weakness or stiffness. They often occur in sleep and may include thrashing movements, fear, screaming and/or bicycling movements of the legs.

Seizures arising from the occipital lobe are more likely to be disturbances of vision, in which the child "sees" things that are not really there.

Epilepsy syndromes

Some children with epilepsy appear to be very similar to other children with epilepsy in terms of how old they are when the seizures begin, what type of seizures they have, their

electroencephalograph (EEG) findings, response to treatment, the way epilepsy affects them over time, and what their future is likely to be.

These children are identified as having a specific epilepsy syndrome. New syndromes are constantly being identified. Some common ones are as follows:

childhood syndromes

Childhood absence epilepsy

(petit mal epilepsy)

This syndrome accounts for 2-4 percent of epilepsy in children and begins between ages 3 and 10. Absence seizures are brief staring spells, associated with a distinctive spike and wave EEG pattern, which tend to occur very frequently. Forty percent of children with this epilepsy syndrome will outgrow it or go into remission by their teenage years.

Juvenile myoclonic epilepsy

This typically begins during the teenage years in otherwise healthy children. The first symptom is usually brief episodes of jerking movements in the arms soon after awakening and they may have generalized seizures also occurring in the early morning hours. Their seizures are usually well controlled with medication but are not likely to be outgrown.

Benign rolandic epilepsy

(also called benign partial epilepsy of childhood)

This syndrome accounts for more than one third of epilepsy beginning in middle childhood between ages 3 and 13. It involves simple partial seizures affecting the face, causing drooling and inability to speak,

which may be followed by a convulsion. Seizures typically occur at night. Otherwise, these children are usually normal and healthy. Ninety-five percent of them outgrow their seizures by age 15.

Infantile spasms (West Syndrome)

These are clusters of rapid, myoclonic jerks, causing a baby to double up and jerk forward with its arms, either bent or extended. The children have a distinctive EEG pattern called hypsarrhythmia. The syndrome is time limited, starting in the first year of life. Many children with infantile spasms, have associated developmental delay and may go on to develop other forms of epilepsy, such as Lennox-Gastaut syndrome. Treatment may include steroid hormones, ACTH and antiepileptic drugs.

Lennox-Gastaut syndrome

A difficult-to-treat epilepsy syndrome with mixed seizures including absence seizures, tonic seizures that cause stiffening, often during sleep, drop attacks, convulsive seizures on waking, and a distinctive EEG pattern. It begins between the ages of 1 and 5. Children often have developmental delay and some mental retardation.

There are also several rare syndromes associated with seizures. These include Rasmussen's syndrome, which produces seizures arising from one side of the brain, and the Landau-Kleffner syndrome, which causes seizures and loss of speech.

seizures and fever

Febrile (fever-caused) seizures affect many children between the ages of 3 months and 6 years. Febrile seizures are not the same as epilepsy, although in rare cases they may be the first seizures experienced by a child who develops epilepsy later on.



Febrile seizures occur when a child's temperature rises rapidly, usually to 102 degrees or higher. There is often a family history of febrile seizures; they are most common

around 18 months of age and affect between 3 and 4 percent of all children. Thirty to 40 percent of children who have a febrile seizure will have another one, but most children grow out of the tendency as they grow older. About 3 percent of children with febrile seizures go on to develop epilepsy.

In children with epilepsy, fever (as well as some drugs, medications and sleep deprivation) may trigger seizures.

seizures and other conditions

Having a seizure is a sign of an underlying condition in the brain. In many cases it is the only sign of a brain disorder. In other cases it may be just one of many symptoms.

Common brain conditions that may also be associated with seizures include tuberous sclerosis, cerebral palsy, mental retardation, autism and neurofibromatosis.

Epilepsy associated with other brain disorders is usually treated in the same way as epilepsy from an unknown cause.

MANAGING SEIZURES

In most cases, seizure management or first aid means keeping a child safe while the seizure runs its course. Fortunately, most seizures are brief and stop within a few minutes.

The first step in any seizure management plan is to get your doctor's advice. He or she knows your child's seizure history and is in the best position to help you plan an appropriate response.

standard first aid for generalized tonic-clonic seizures

- Protect the child from injury while the seizure continues, but don't forcefully restrain movements.
- Whenever possible, try to lay the child on a soft surface and turn on one side.
- Place something flat and soft under the head; loosen tight neckwear.
- Do not place anything in the mouth.
- CPR should not be given during a seizure.
- Record approximately how long the seizure lasts.
- As the jerking slows down, make sure breathing is unobstructed and 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 re-orient him or her as consciousness returns.

what to tell your doctor

Most doctors will never see your child have a seizure – they don't happen often in the doctor's office. It will help the doctor if you write down

what the child was doing just before the seizure began, what happened during the seizure, how long it lasted, and how quickly your child recovered afterwards.

emergency aid

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

However, if it lasts more than 5 minutes without any sign of slowing down, is unusual in some way, or if a child has trouble breathing afterwards, appears to be injured or in pain, or recovery is different from usual, call 911 for emergency help.

It is always a good idea to discuss with your doctor in advance what to do if your child should have a prolonged seizure.

special circumstances

For some children who have convulsive seizures that are prolonged - lasting several minutes - or occur in clusters, there are new treatments available that parents or caregivers can administer orally, rectally, or by injection to bring this type of seizure to an end.

Ask your doctor whether these treatments would be appropriate for your child.

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managing status epilepticus

Prolonged or clustered seizures sometimes develop into non-stop seizures, a condition called status epilepticus.

Status epilepticus is a medical emergency. It requires hospital treatment to bring the seizures under control. If your child has had episodes of non-stop seizures that had to be treated in the

emergency room, you will want to have a plan of action ready in case they occur again.

Ask the doctor if there are any new treatments for use at home or at school to stop a seizure from developing into status epilepticus.

If your child is experiencing continuous seizures, call an ambulance. Do not attempt to transport an actively seizing child in your car unless an ambulance is not available.

Be aware of where the nearest hospital is and how long it takes to get there. If you live a long way from the hospital, you may plan to call earlier than you would if it were closer.



If there are several hospitals nearby, ask your doctor in advance which one to call.

Consider arranging for standing orders prepared by the doctor to be kept in the emergency room so the seizure can be managed as your doctor directs. Ask for a copy for yourself if you and your child

travel out of town.

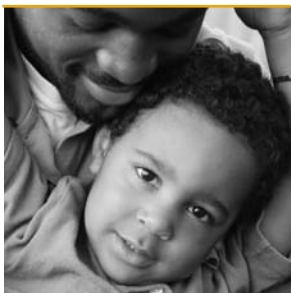
Leave detailed written instructions with babysitters or adult caregivers. If you have been instructed in the use of in-home therapy, make sure that a responsible caregiver also receives instruction.

Fortunately, most seizures, even those that are prolonged, end without injury. The important thing is to work with your doctor so that you have a plan to follow when they occur.

managing partial seizures

A child who has partial seizures that affect emotions or sense of the world around him or her may be intensely frightened by the seizures.

Children with this type of epilepsy need lots of reassurance – and an adult who keeps track of how often the seizures occur. If they become prolonged and frequent, emergency treatment may be necessary.



Managing complex partial seizures requires gentle monitoring during the seizure; keeping hazards out of the way, reassuring the child in a calm voice, and keeping track of how long the seizure lasts.

Prolonged confusion and clusters of complex partial seizures may also require at-home therapy as prescribed, or emergency treatment.

TREATMENT

Childhood epilepsy is usually treated with seizure-preventing medicines called antiepileptic or anticonvulsant drugs.

If the drugs don't work or if the child has a lot of side effects, surgery, the ketogenic diet, or vagus nerve stimulation (VNS) may be tried.

medication

Children take the same antiepileptic medications as adults do. Medication may be prescribed as tablets, sprinkles, capsules or in syrup.

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

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

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.

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finding the right drug

The search for the best medication for any individual child may take quite a long time.

Children, like adults, respond to medications in different ways. Several drugs or different combinations of drugs may have to be tried in an effort to get the seizures under control.

The goal of treatment is to achieve the greatest level of control with the lowest level of side effects, at the lowest possible dose.

Common side effects from antiepileptic drugs include fatigue, nausea, changes in vision, and weight gain.

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 go away (or become less of a problem) as the child becomes accustomed to it.

Helping the treatment work

- Ask your doctor about possible side effects associated with the medicine and what you should do if you see them. Let your doctor know about any change in behavior or academic performance.
- 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.
- Do not 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.

Parents often worry that long term use of antiepileptic drugs may lead to drug abuse or dependency in their children.



Most doctors say there is very little if any abuse of these medications among young people with epilepsy. In fact, refusing to take the medication is a more common form of rebellion among teenagers.

Taking responsibility

When children are small, the parents are the ones who make sure the medications are taken on time. As children get older, they may take on more of this responsibility themselves.

Even with the best of intentions, however, children may forget. One way of monitoring whether the medication is being taken is to count out (or teach the child to count out) each day's doses and store them in a special container so you can track whether or not the tablets or capsules have been taken.

If a school-aged child has to take medication during the day, check with the school about what arrangements should be made. Most school systems will not allow children to give themselves medication at school, but will arrange for the school nurse or other school official to do so.

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

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

The generator is connected to lead wires under the skin, the ends of which are wound around the vagus nerve. The operation which places the device can be done on an inpatient or outpatient basis.

specialized care

Specialized care for children with hard-to-treat epilepsy is available at special centers around the country. They offer in-depth evaluation, surgery, the ketogenic diet, and VNS therapy.



For information about sources of specialized care near you, contact the Epilepsy Foundation in your community or the national office at 1-800-332-1000.

YOUR CHILD AT HOME

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

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.

However, 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. In general, children with epilepsy should be disciplined just as you would discipline any other child. 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.

But the rest of the family -- grandparents, aunts, cousins -- may have beliefs about this condition that hail from an earlier time. They may think it is somehow linked to mental illness (it isn't), or 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 to rest.

Your commitment to helping your child live as normally and actively as his or her condition permits, and to treat your child as much as possible just like any other child, will guide their response as well.



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 without feeling guilty about it.



YOUR CHILD AT SCHOOL

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.

meeting the teacher

First, take time to meet with your child's teacher before the beginning of each school year to discuss how epilepsy affects your child, what type of seizures he or she has, and how you would like the teacher to handle the seizures when they occur.

Since seizures are a common problem, many teachers will have had other students with epilepsy. If your child's teacher is unfamiliar with seizures and would like information about them, contact your local Epilepsy Foundation.

Videos, pamphlets and first aid presentations available from the Epilepsy Foundation have a basic message: that students with seizures belong in school and are in no way any kind of threat to other children.

With information, reassurance, and plenty of opportunities to ask questions, other children can also learn to take seizures in stride and continue to accept the child who has them.

But gaining acceptance is not the only challenge for children with seizures.

Achievement

While many children with epilepsy test within the same range as other children, and are quite normal and healthy, their achievement at school may be lower.

There may be several reasons for this, including side effects from the medication, days spent out of school for tests or doctor visits, and anxiety about having seizures at school. Memory or attention may also be affected.

After a seizure a child may be unable to remember anything that happened the previous day or immediately afterwards. Testing for learning disabilities may reveal specific difficulties related to where the seizures are occurring in the child's brain.

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 and the Americans with Disabilities Act) and state laws protect children with disabilities from discrimination on the basis of disability.

DEALING WITH RISK

swimming

A child with epilepsy - or any child – should never swim alone, or be on a boat or close to water (including backyard wading pools) without a flotation device or life jacket.

- Carefully supervise children near water.
- Make sure an adult is present who knows your child has epilepsy and is a good enough swimmer to help if your child has a seizure in the water.
- Tell lifeguards or swimming instructors at local pools or beaches that your child has seizures.

If a child has a seizure in the water, he or she should be evaluated by a medical professional if there is the possibility that water has been swallowed or breathed into the lungs. In this case, call 911.

other sports

Unless your child's doctor recommends otherwise, sports activities and other exercise are as beneficial to a child with epilepsy as they are to any other child.

In general, school sports activities and gym should be open to all children, including children with seizures. Safety measures such as harnesses, shock absorbing mats and adult supervision should reduce risks.

Coaches and other officials should be aware that a child has seizures, and how the parents want them to be managed.

Wearing safety helmets when riding a bicycle, or for sports where head injury is possible, should reduce risk.

RESOURCES

help with other disabilities

When your child has other disabilities in addition to seizures, you may get help from the following organizations:

The ARC of the United States

(formerly Association for Citizens with Retardation)

1010 Wayne Avenue, Suite 650
Silver Spring, MD 20190
www.thearc.org

Autism Society of America

7910 Woodmont Avenue, Suite 300
Bethesda, Maryland 20814-3067
www.autism-society.org

United Cerebral Palsy Association

1660 L Street, NW, Suite 700
Washington, DC 20036
www.ucp.org

Learning Disabilities Association of America

4156 Library Road
Pittsburgh, PA 15234
www.ldanatl.org

National Tuberos Sclerosis Association

801 Roeder Road, Suite 750
Silver Spring, MD 20910
www.ntsasa.org

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help from the epilepsy foundation

The Epilepsy Foundation is a non-profit, voluntary organization with affiliates nationwide. It works for children (and adults) with epilepsy through support of research, education, advocacy and service.

Local Epilepsy Foundations in many parts of the country offer parent groups, programs for children such as camping and family recreation, respite care when children have severe and frequent seizures, information and education about the condition, advocates who can work with parents on school planning issues, and special seminars and conferences.

The Epilepsy Foundation's web site (www.epilepsyfoundation.org) offers news and information on an ongoing basis. A national toll free information service (1-800-332-1000) is available to answer your questions.

Our catalog offers books and videos on epilepsy in childhood, as well as pamphlets and manuals on schooling issues, parent rights, medications, surgery and camping. The Foundation publishes newsletters for children, and a bi-monthly magazine, *EpilepsyUSA*.



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