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Epilepsy FAQ

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Epilepsy FAQ

Frequently Asked Questions about Epilepsy

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Maintained by Andrew Patrick (andrew@calvin.dgbt.doc.ca). New material and suggestions are always welcome.

URL for this FAQ and other information:
<http://debra.dgbt.doc.ca/~andrew/epilepsy/>

NOTES

Please note that this Epilepsy information MAY NOT BE ACCURATE OR COMPLETE. Anyone with serious questions about Epilepsy should consult their doctor. Some of this material was prepared by Epilepsy Ottawa-Carleton and Epilepsy Ontario, and it is used with

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Questions Covered in this Document

* Basic Information

- o What does "Epilepsy" mean?
- o Is Epilepsy a disease?
- o What is a seizure?
- o What is an aura?
- o When was Epilepsy discovered?

* People with Epilepsy

- o What kind of people have Epilepsy?
- o How many people have Epilepsy?
- o Does Epilepsy strike at any particular age?
- o Does Epilepsy occur more in some cultures?

* Types of Seizures

- o Are there different types of seizures?
- o What is the difference between partial and general seizures?
- o What are partial seizures?
- o What are complex partial seizures?
- o What are absence (petit mal) seizures?
- o What are tonic-clonic (grand mal) seizures?
- o What are other types of seizures?
- o What are "status" seizures?
- o What are pseudoseizures?
- o How do you distinguish epileptic seizures from pseudoseizures?
- o Can seizures occur if a person does not have Epilepsy?
- o What are the seizures like?
- o What does it feel like to have a seizure?
- o How long do the seizures last?
- o Is there such a thing as a "minor" case of Epilepsy?

* Causes and Triggers

- o What causes Epilepsy?
- o Is Epilepsy inherited?
- o Is Epilepsy contagious?
- o Is it caused by a virus?

- o Can certain things trigger seizures?
- o Can seizures be triggered by flashing lights?
- o Can certain foods or drinks cause seizures?
- o Can lack of sleep cause seizures?
- o Can low blood sugar trigger seizures?
- o Can Nutrasweet (Aspartame) trigger seizures?
- o Does alcohol affect seizures?

* First Aid for Seizures

- o How can I help someone who is having a seizure?
- o What if my child has a seizure during his sleep?

* Diagnosis

- o How is Epilepsy diagnosed?
- o What types of doctors can diagnose and treat Epilepsy?
- o Can a person with Epilepsy have a false negative EEG?
- o Can a person have a false positive EEG for Epilepsy.
- o Is my child having absence seizures or just day dreaming?
- o What conditions are sometimes mis-diagnosed as Epilepsy?
- o Can seizures go un-noticed?

* Treatments

- o Is there a cure for Epilepsy?
- o Is it fatal?
- o What kinds of treatments are available?
- o Are there drug treatments for Epilepsy?
- o How do drugs work to control seizures?
- o What drugs are used to treat Epilepsy?
- o How effective are the drug treatments?
- o Do these drugs have side effects?
- o What is a "blood level"?
- o What are the symptoms of too high a drug level?
- o How much do the drugs cost?
- o Is it necessary for all people with Epilepsy to be on medication?
- o When is surgery used to treat Epilepsy?
- o What is the likelihood that my child will outgrow a seizure disorder?
- o Do non-traditional approaches help?
- o Does transcendental meditation have any effect on Epilepsy?
- o Does biofeedback help?
- o Is there a special diet for people with Epilepsy?
- o What is a ketogenic diet?

* Living with Epilepsy

- o Can people living with Epilepsy lead normal lives?
- o What can people with Epilepsy do to help their health?
- o Who should know that I have Epilepsy?
- o Is there prejudice against people with Epilepsy?
- o Are there any problems having children?
- o Can medications for controlling Epilepsy harm a nursing baby?
- o Can people living with Epilepsy drive a car?
- o Can people living with Epilepsy go swimming?
- o Can Epilepsy lead to problems at school?
- o Can Epilepsy cause emotional problems?
- o Can Epilepsy lead to problems with self-esteem?

* Working With Epilepsy

- o What occupations are not appropriate for people with Epilepsy?
- o Can people with Epilepsy fly a plane?
- o Is there a problem with job safety?
- o Can an employer ask about Epilepsy on a job application?
- o Can an employer ask about Epilepsy during a job interview?
- o Can I be fired because I have Epilepsy?
- o Can people with Epilepsy get social assistance?

* Epilepsy and Other Disorders

- o Is Epilepsy related to other neurological problems?
- o Is Epilepsy related to mental illness?
- o Can Epilepsy affect intelligence?
- o Is there a link between memory loss and Epilepsy?
- o Is Epilepsy related to asthma?
- o Are there any diseases that persons with Epilepsy more prone to?

* Miscellaneous

- o Do animals get Epilepsy?
- o Can dogs sense a seizure in humans before it strikes?

* More Information

- o Where can I get more information about Epilepsy?
- o What books are available on Epilepsy?
- o Where can I find information on the Internet about Epilepsy?

Q: What does "Epilepsy" mean?

The word "Epilepsy" is derived from a Greek word meaning "a condition of being overcome, seized, or attacked." People used to believe that the seizure was caused by a demon, and Epilepsy became known as a sacred disease. This is the background to the myths and fears that surround Epilepsy; myths that colour people's attitudes and make the goal of a normal life more difficult than it needs to be for people who have Epilepsy. The word "Epilepsy" means nothing more than the tendency to have seizures.

Q: Is Epilepsy a disease?

Epilepsy is not a disease. It is a sign or symptom of an underlying neurological disorder.

Q: What is a seizure?

The brain is a highly complex and sensitive organ. It controls and regulates all our actions. It controls motor movements, sensations, thoughts, and emotions. It is the seat of memory, and it regulates the involuntary inner workings of the body such as the function of the heart and the lungs.

The brain cells work together, communicating by means of electric signals. Occasionally there is an abnormal electrical discharge from a group of cells, and the result is a seizure. The type of seizure will depend upon the part of the brain where the abnormal electrical discharge arises.

Q: What is an aura?

Before the onset of a seizure some people experience a sensation or warning called an "aura". The aura may occur far enough in advance to give the person time to avoid possible injury. The type of aura experienced varies from person to person. Some people feel a change in body temperature, others experience a feeling of tension or anxiety. In some cases, the epileptic aura will be apparent to the person as a musical sound, a strange taste, or even a particular curious odour. If the person is able to give the physician a good description of this aura, it may provide a clue to the part of the brain where the initial discharges originate. An aura could occur without being followed by a seizure, and in some cases can by itself be called a type of simple partial seizure.

Q: When was Epilepsy discovered?

Epilepsy is the oldest known brain disorder. It was mentioned more than 2,000 years before Christ. References can be found in ancient Greek texts and in The Bible. It wasn't until the mid 1800's, however, that Epilepsy was given serious study. Sir Charles Locock was the first to introduce a sedative that aided in controlling seizures in 1857. In 1870, John Hughlings Jackson identified the brain's outer layer, the cerebral cortex, as the part involved in Epilepsy. Hans Berger demonstrated that the electrical impulses of the human brain could be recorded in 1929.

Topic: People with Epilepsy

Q: What kind of people have Epilepsy?

Virtually everyone can have a seizure under the right circumstances. Each of us has a brain seizure threshold which makes us more or less resistant to seizures. Seizures can have many causes, including brain injury, poisoning, head trauma, or stroke; and these factors are not restricted to any age group, sex, or race and neither is Epilepsy.

Q: How many people have Epilepsy?

Epilepsy is far more common than most of us realize. Current estimates indicate that more than one per cent of the population have had, or will have, some form of Epilepsy in their lifetime.

Q: Does Epilepsy strike at any particular age?

Epilepsy can strike anyone at any age. However, most persons who develop seizures during their formative years tend to experience a reduction in the intensity and frequency of their seizures as they grow older. In many cases the Epilepsy will disappear completely. 50% of all cases develop before 10 years of age.

Q: Does Epilepsy occur more in some cultures?

Epilepsy occurs more frequently in some cultures. In Tanzania, 4% of the population experiences severe seizure disorders. In this case, genetic predisposition to lower seizure thresholds is known to exist. In Canada, 1-2% of the population has Epilepsy.

Topic: Types of Seizures

Q: Are there different types of seizures?

Many varieties of epileptic seizures occur, and frequency and form of attacks vary greatly from person to person. With modern methods of treatment, however, most cases can be fully controlled. Because there are so many nuances in Epilepsy and so many different kinds of seizures, a specific classification system is being promoted by the International League Against Epilepsy. The International Classification of Epilepsy Seizures has been adopted by the medical community and is gradually replacing outdated seizure terminology including "grand mal" and "petit mal".

The new classification scheme describes two major types of seizures: "partial" and "generalized". It also divides each of these categories into subcategories including simple partial, complex-partial, absence, tonic-clonic, and other types.

Q: What is the difference between partial and general seizures?

The distinction between "partial" and "generalized" seizures is the most important feature of the new classification system. If the excessive electrical discharge in the brain is limited to one area, the seizure is partial. If the whole brain is involved, it is generalized. In all, there are over 30 different seizure types. Therefore, the new classification format subdivides the partial and generalized Epilepsies into a number of different categories.

Q: What are partial seizures?

Partial seizures (formerly known as focal seizures) with elementary symptomology are often referred to as simple partial. During this type of seizure the patient can experience a range of strange or unusual sensations including sudden, jerky movements of one body part, distortions in hearing or seeing, stomach discomfort, or a sudden sense of fear. Consciousness is not impaired. If another seizure type follows, these sensations may be referred to as an "aura".

Q: What are complex partial seizures?

Complex-partial seizures (formerly psychomotor or temporal lobe Epilepsy) are characterized by a complicated motor act involving impaired consciousness. During the seizure the patient appears dazed and confused. Purposeless behaviours such as random walking, mumbling, head turning, or pulling at clothing may be observed. Usually, these so-called "automatisms" cannot be recalled by the patient. In children

this seizure may consist of staring or lip-smacking, and therefore may be confused with the absence seizure described below.

Q: What are absence (petit mal) seizures?

Generalized absence seizures (formerly petit mal) are characterized by 5 to 15 second lapses in consciousness. During this time the patient appears to be staring into space and the eyes may roll upwards. Absences are not preceded by an aura and activity can be resumed immediately afterwards. Typically, they occur in children and disappear by adolescence. They may, however, evolve into other seizure types, such as complex-partial or tonic-clonic. The occurrence of absences in adulthood are rare.

Q: What are tonic-clonic (grand mal) seizures?

The tonic-clonic (formerly grand mal) seizure is a generalized convulsion involving two phases. In the tonic phase, the individual loses consciousness and falls, and the body becomes rigid. In the clonic period, the body extremities jerk and twitch. After the seizure, consciousness is regained slowly. If the tonic-clonic seizure begins locally (with a partial seizure) it may be preceded by an "aura". These seizures are said to be secondarily generalized.

While the tonic-clonic seizure is the most visible, obvious type of Epilepsy, it is not the most common. Partial seizures are more frequently encountered and occur in 62% of all Epilepsy patients. Complex-partial seizures account for approximately 30% all cases.

Q: What are other types of seizures?

Benign rolandic epilepsy is an epileptic syndrome occurring in young children that is age limited (you stop having seizures in the teen years) . Salivation, twitching of the mouth or upper extremity on one side are typical manifestations. Seizures occur almost exclusively nocturnally.

Juvenile myoclonic epilepsy is an epilepsy characterized by onset in childhood or adolescence and is associated with extremity jerking or generalized tonic clonic seizures ('grand mal') within an hour or two of waking from sleep. Seizures which may be precipitated by sleep deprivation, alcohol intake or coffee (strange) tend to occur in the morning.

Please contact your local Epilepsy association or clinic for additional information. Other seizure terms include: Atonic (Drop

Attacks), Myclonic, Infantile Spasms, Nocturnal, Photosensitive, Visual, Musicogenic, Jacksonian, Sensory, Bilateral Myclonus, Atkinetic, Autonomic, Prolonged seizures, and Ictal State.

Q: What are "status" seizures?

Status epilepticus is the term used to describe recurrent seizures without recovery of consciousness between attacks. This is a medical emergency and can be life threatening, or cause brain damage. Immediate action to get the necessary medical care should be taken.

Q: What are pseudoseizures?

Pseudoseizures (or psychogenic seizures) are quite common and can occur in people who have, or do not have, Epilepsy. The attacks are triggered by a conscious or unconscious desire for more care and attention. The seizures start with rapid breathing, triggered by mental stress, anxiety, or pain. As the person breaths rapidly, they build up carbon dioxide in their body and change their chemistry. This can cause symptoms very much like Epileptic seizures: prickling in the face, hands, and feet, stiffening, trembling, etc. The appropriate treatment for pseudoseizures is to calm the person and start them breathing at a normal rate. Treatment should also involve investigating the mental and emotional factors that led to the pseudoseizure.

Q: How do you distinguish epileptic seizures from pseudoseizures?

Epileptic seizures and pseudoseizures are distinguishable both by their nature and symptoms, but the diagnosis can be difficult. Epileptic seizures are caused by a change in how the brain cells send electrical signals to each other, while pseudoseizures are triggered by a conscious or unconscious desire for more care and attention. Thus, measuring brain activity with an EEG and video telmetry is important for distinguishing epileptic and pseudoseizures. Also, pseudoseizures often lack the exhaustion, confusion, and nausea that is associated with epileptic seizures. Psychogenic seizures can occur in people who also experience epileptic seizures.

Q: Can seizures occur if a person does not have Epilepsy?

Epilepsy is a chronic condition of recurrent unprovoked seizures. Isolated seizures and provoked seizures (e.g., drug or alcohol induced) are not Epilepsy even though the events are real seizures. There are many types of non-epileptic seizures. Non-epileptic seizures differ from epileptic seizures in that there is usually no evidence of abnormal electrical activity in the brain after the seizure, and they do not occur repeatedly. Some of the more common causes of

non-epileptic seizures are: low blood sugar, fainting, heart disease, stroke, migraine headaches, kinked blood vessels, narcolepsy, withdrawal, and extreme stress or anxiety.

Q: What are the seizures like?

The nature of the seizures varies depending upon the type of Epilepsy the individual has. Some seizures may be very noticeable while some may go completely unrecognized. With the most common types of seizures there is some loss of consciousness, but some seizures may only involve small movements of the body or strange feelings. The different seizures types have certain characteristics that accompany them.

Q: What does it feel like to have a seizure?

Epilepsy is a broad classification for a wide variety of seizures, so different people's seizures can be very different. Common feelings associated with seizures include uncertainty, fear, physical and mental exhaustion, confusion, and memory loss. Some types of seizures can produce visual and auditory phenomena, while others can involve a "blank" feeling. If a person is unconscious during a seizure there may be no feeling at all. Many people also experience an "aura" before the seizure itself.

Q: How long do the seizures last?

Depending on the type of seizure, they can last anywhere from a few seconds to several minutes. In rare cases, seizures can last many hours. For example, a tonic-clonic seizure typically lasts 1-7 minutes. Absence seizures may only last a few seconds, while complex partial seizures range from 30 seconds to 2-3 minutes. "Status Epilepticus" refers to prolonged seizures that can last for many hours, and this can be a serious medical condition. In most cases, however, seizures are fairly short and little first aid is required.

Q: Is there such a thing as a "minor" case of Epilepsy?

There are over 30 types of seizures, and some types are more severe than others. Long tonic-clonic convulsions, for example, can produce more physical and mental effects than shorter partial seizures. Some people may experience very frequent seizures (every few hours), while others can go for months or years without a seizure. Also, some seizures are easily controlled by drug therapies, while others may continue regardless of the medication that is tried.

Topic: Causes and Triggers

Q: What causes Epilepsy?

There is no single cause of Epilepsy. Many factors can injure the nerve cells in the brain or the way the nerve cells communicate with each other. In approximately 65% of all cases there is NO known cause. The following are some of the most frequently identified causes:

- o Head injury that causes scaring of the brain tissue.
- o Trauma at birth, or high fever.
- o Excessively rough handling or shaking of infants.
- o Certain drugs or toxic substances when administered in large doses.
- o Interruption of blood flow to the brain caused by stroke, tumour, or certain cardiovascular problems.
- o Diseases which alter the balance of blood or its chemical structure, or diseases that damage the nerve cells in the brain.

When physicians can identify the underlying disorder, such as those mentioned above, the condition is referred to as "Symptomatic" Epilepsy. In some cases, however, the underlying disorder can't be identified and this is called "Idiopathic" Epilepsy.

Q: Is Epilepsy inherited?

In most cases Epilepsy is not inherited. In a few cases the tendency towards Epilepsy might be inherited, but even with this tendency certain conditions must exist in the brain before a person will experience epileptic seizures. It is most unlikely that children will inherit the disorder.

Q: Is Epilepsy contagious?

Epilepsy is in no way contagious. No one can get the disorder by talking to, kissing, or touching somebody with Epilepsy. Epilepsy can only be transmitted through hereditary transfer. Epilepsy that runs in families suggests an underlying metabolic or genetic etiology, and this is the least common of all Epilepsy causes.

Q: Is it caused by a virus?

Epilepsy can be the result of an infection or disease. Some conditions known to have a risk of resulting in Epilepsy are meningitis, viral encephalitis, and less frequently mumps, measles, diphtheria, and abscesses.

Q: Can certain things trigger seizures?

In some cases, epileptic seizures can be triggered by things that happen in the environment. Seizures can be triggered by flashing lights or sudden changes from dark to light (or vice versa). Other people can react to loud noises or monotonous sounds, or even certain musical notes. It is important for people with Epilepsy to learn what kinds of events can trigger seizures for them.

Q: Can seizures be triggered by flashing lights?

"Photosensitive Epilepsy" is the name given to a form of the disorder where seizures are triggered by flickering or flashing lights. Though it occurs more frequently in girls aged 6-12, it can occur at any age and regardless of gender.

Q: Can certain foods or drinks cause seizures?

People with Epilepsy should have regular meals at regular intervals and pay attention to what they eat and drink. Prescription and non-prescription drugs, as well as food additives, may interact with anti-convulsant drugs. Alcohol can lower seizure thresholds.

Q: Can lack of sleep cause seizures?

Excessive sleep deprivation can lower seizure thresholds and possibly result in a seizure. Lack of sleep is known to be an important precipitating factor in causing seizures. Other factors that can lower seizure thresholds are high fever, increased excitement, and changes in body chemistry. It is important for people with Epilepsy to learn what kinds of events can trigger seizures for them.

Q: Can low blood sugar trigger seizures?

Hypoglycemia (low blood sugar) can induce epileptic-type seizures. This condition can be caused by diet or by drugs such as insulin. This is not really Epilepsy since it is not recurrent seizures that are due to abnormal brain activity. Here the seizures are directly caused by the blood sugar levels.

Q: Can Nutrasweet (Aspartame) trigger seizures?

In 1984, there were 3 reports about large amounts of Aspartame causing a lowering of the seizure threshold and therefore increasing seizure activity. The Centre for Disease Control in Atlanta did a review of this and were unable to find any cause or effect relationship at normal doses. More recently, Aspartame has been found to be unsuitable for

some children with generalized absence Epilepsy. A Queen's University study looked at the brain-wave patterns in 10 children and the effects of the artificial sweetener "Nutrasweet". A 40% increase in abnormal brain-wave activity associated with absence seizures was found in this study. However, there was no effect on the actual number of seizures. Research on this topic is continuing.

Q: Does alcohol affect seizures?

Alcohol can raise and then lower the seizure threshold, and thus increases the tendency to have a seizure. More important are interactions between alcohol and seizure medicines. Also, some drugs of abuse, especially cocaine and amphetamines, can cause seizures. Some prescription medications when taken in large doses can also bring on seizures.

Topic: First Aid for Seizures

Q: How can I help someone who is having a seizure?

The appropriate behaviour for helping someone who has a seizure depends on the type of seizure it is. While a person experiencing a tonic-clonic seizure may require some first aid, in most cases there is little that can be done.

Tonic-Clonic (Grand Mal)

This type of seizure is often the most dramatic and frightening, but it is important to realize that a person undergoing an epileptic seizure is usually unconscious and feels no pain. The seizure usually lasts only a few minutes, and the person does not need medical care. These simple procedures should be followed:

1. Keep calm. You cannot stop a seizure once it has started. Let the seizure run its course. Do not try to revive the person.
2. Ease the person to the floor and loosen clothing.
3. Try to remove any hard, sharp, or hot objects that might injure the person. It may be necessary to place a cushion or soft item under their head.
4. Turn the person on his or her side, so that the saliva can flow from the mouth.
5. Do NOT put anything in the person's mouth.
6. After the seizure the person should be allowed to rest or to sleep if necessary.
7. After resting most people carry on as before. If the person is not

at home and still seems groggy, weak, or confused, it may be better to accompany them home.

8. In the case of a child having a seizure, contact a parent or guardian.
9. If the person undergoes a series of convulsions, with each successive one occurring before he or she has fully recovered consciousness, or a single seizure lasting longer than 10 minutes, you should immediately seek medical assistance.

Absence (Petit Mal)

No first aid is required.

Complex-Partial (Psychomotor or Temporal Lobe)

1. Do NOT restrain the person. Protect him or her by moving sharp or hot objects away.
2. If wandering occurs, stay with the person and talk quietly.

Simple-Partial (Focal)

No first aid is required.

Q: What if my child has a seizure during his sleep?

Children are usually awakened by seizures that occur while they sleep. Thus, a parent of a child with a known seizure disorder is usually aware when their child has seizures during the night. Only in those rare cases where a child vomits or experiences other problems during a seizure is there a need to worry.

Topic: Diagnosis

Q: How is Epilepsy diagnosed?

The diagnosis and evaluation of Epilepsy requires the physician to know all about the seizures - when they started, the patient's appearance before, during, and after a seizure, and any unusual behavioural occurrences. A background of the family's health history is also useful. In addition, an electroencephalogram (EEG) may help detect areas of increased nerve cell activity.

Q: What types of doctors can diagnose and treat Epilepsy?

Any licensed physician is qualified to treat Epilepsy. There are doctors who specialize in neurological disorders, and these neurologists can be found practicing in many hospitals and private practices. Epileptologists may work in an Epilepsy clinic, as well as in private practices. Usually a referral is required from another physician in order to see a Neurologists and Epileptologists. Some people also consult alternative health practitioners who specialize in holistic healing, acupuncture, or chiropractic treatments.

Often, the first doctor to diagnose Epilepsy is the family doctor. Most of them have had some experience with it, and will be the one to refer a person with Epilepsy to a specialist initially. Pediatricians are also well aware of Epilepsy, since about two-thirds of all Epilepsy occurs before the age of 14. A neurologist has specialized training in the disorders of the brain and nervous system. A neurosurgeon, psychiatrist, or psychologist may also get involved if the circumstances require them.

Q: Can a person with Epilepsy have a false negative EEG?

An EEG measures the electrical activity on the surface of the brain. An EEG may appear to be normal if the abnormal electrical activity is occurring deeper in the brain than the EEG is able to monitor.

Q: Can a person have a false positive EEG for Epilepsy.

Many people who do not have Epilepsy may have some "epileptiform" activity on an EEG. However, this does not prove that they have a seizure disorder. Reading EEG's is a highly skilled activity, and a diagnosis of Epilepsy is based on the clinical picture as well as the EEG. Other tests, such as CT scans and MRI scans, may be performed to confirm any findings.

Q: Is my child having absence seizures or just day dreaming?

A child having an absence seizure may appear to the onlooker as if they are day dreaming or just staring into space. What may be happening is a sudden period of altered consciousness. To be able to tell the difference, close observations might have to be done. Usual behavioral characteristics of a absence seizure may include: eye blinking, chewing of the mouth, and perhaps a slight rhythmic movement of the facial muscles, head, or arms. During the seizure the child may not respond to verbal or physical stimulation. Immediately after the seizure, the child is able to resume normal activity. If you observe unusual behaviour in your child, a visit to a neurologist should be arranged through your family doctor.

Q: What conditions are sometimes mis-diagnosed as Epilepsy?

Seizures occurring as a result of alcohol withdrawal, fever, or hypoglycemia can be mistaken for Epilepsy. Other causes of seizures that do not indicate Epilepsy are strokes, migraine headaches, calcified blood vessels, narcolepsy, and psychogenic or pseudoseizures.

Q: Can seizures go un-noticed?

The symptoms of seizures are not always noticeable for on-lookers or for the person who is experiencing the seizure. Seizure may result in rigidity in the body, convulsions, chewing of the mouth, unusual behaviors, or loss of consciousness. Some symptoms may be less apparent, such as disorientation or unusual sensations. Milder symptoms do not mean that the seizure is of less importance.

Topic: Treatments

Q: Is there a cure for Epilepsy?

There is no known "cure" for Epilepsy. Medications can often control seizures, but they are not a cure. Some forms of Epilepsy occur only in childhood, and the person is said to have outgrown the seizures. In some cases there is a spontaneous remission of the seizure disorder. Sometimes, surgery to remove the part of the brain in which the seizures originate can produce a complete and permanent stop to seizures.

Q: Is it fatal?

Epilepsy itself can cause death if prolonged repeated seizures ("status epilepticus") are not treated properly. Such deaths are very rare, however. More common is death due to hazards or accidents that occur when someone has a seizure unexpectedly in a potentially dangerous situation.

Q: What kinds of treatments are available?

When a physician diagnoses Epilepsy, a specific treatment can be recommended. The treatment prescribed by the physician is designed to control the seizures and help the patient to carry on a healthy life, participating in all normal activities, including most sports. The two major kinds of treatments are drug therapy and surgery.

Q: Are there drug treatments for Epilepsy?

Treatment of Epilepsy is primarily through the use of special anti-convulsive drugs. There are many different types of these drugs, and the type prescribed will depend upon the particular needs of the individual. The drugs are prescribed either alone or in a combination. The various drugs or combination of drugs control different types of seizures.

Q: How do drugs work to control seizures?

The drugs used to control seizures are called anticonvulsants. How they stop the seizures, change the seizure threshold, or prevent electrical discharges from occurring is not fully known. The neurochemical basis for their action is also unknown. Research has shown that some of the drugs can block the spread of abnormally fast nerve impulses in the brain, while others can increase the flow of chloride ions, which stabilize the nerve cells. Research is still being done in this area.

Q: What drugs are used to treat Epilepsy?

There are many different drugs used to treat Epilepsy. Some of the more common ones are: Tegretol (carbamazepine), Dilantin (phenytoin), Mysoline (primidone), Epival (valproate), Frisium (clobazam), Rivotril (clonazepam), Mogadon (nitrazepam), Phenobarbital, Depakene (valproic acid), Zarontin (ethosuximide), Neurontin (gabapentin), Lamictal (lamotrigine), Sabril (vigabatrin). There are also many new drugs under development.

The choice of drug is determined by the type of seizure, the side effects of the drugs, and the age and health of the person. Often a number of drugs, and combinations of drugs, have to be tried until the seizures are brought under control.

Q: How effective are the drug treatments?

Most epileptic seizures are controlled by special anti-convulsive drugs prescribed by a physician. About 50 per cent of those who take this medication will have their seizures eliminated; 30 per cent will have their seizures reduced in intensity and frequency to the point where they can live and work normally. The remaining 20 per cent are either resistant to the medication, or else they require such large dosages of the drug to control the seizures that it is preferable to accept partial control.

Q: Do these drugs have side effects?

Many medications for Epilepsy have side effects. These can range from mild to severe, and will differ depending on the drug and dosage. Some of the more common side effects of anti-epileptic drugs are: drowsiness, dizziness, nausea, irritability, and hyperactivity.

Q: What is a "blood level"?

"Blood level" refers to the amount of anticonvulsant in the blood. It is measured with a simple blood test and is used to help determine if a patient's symptoms may be due to toxicity or to side effects of medication. It is also used to determine if the patient is taking enough medication to prevent seizures. The therapeutic range for different anti-convulsants has been determined by testing blood levels in thousands of patients whose seizures are controlled and who are not experiencing toxic effects.

Q: What are the symptoms of too high a drug level?

Too high of a drug level may cause a person to experience side effects such as drowsiness, confusion, breakthrough seizures, unsteadiness, and nausea. This may require a reduction in dosage or a change to a different medication.

Q: How much do the drugs cost?

The cost of the anticonvulsant drugs will depend on the dosage levels needed, the drug being used, and the amount in each prescription. There is usually a difference in price between a drug's brand name and its generic equivalent. Ask your doctor or pharmacist if a generic one is available for you to use, and if it is appropriate.

Q: Is it necessary for all people with Epilepsy to be on medication?

Treatment of Epilepsy is primarily through the use of anticonvulsive drugs. There are many different types of drugs and the type prescribed will depend upon the particular seizure pattern of the individual. If someone has been seizure free for several years, the doctor may decide to slowly withdraw the medication.

Q: When is surgery used to treat Epilepsy?

Surgery is used only when medication fails and only in a small percentage of cases where the injured brain tissue causing the seizures is confined to one area of the brain and can be safely removed without damaging personality or functions.

Q: What is the likelihood that my child will outgrow a seizure disorder?

The likelihood of a child outgrowing a seizure disorder is difficult to answer. Sometimes children do outgrow Epilepsy, while for others the seizures may stay the same or intensify with age. Some people experience the same type of seizures throughout their lifetime. Some epilepsies are known to almost always remit (for example, Benign Rolandic Epilepsy or Epilepsy with centrotemporal spikes and rolandic seizures), some are known to usually remit (e.g., childhood absence) and some are known to almost never remit (e.g., Juvenile Myoclonic epilepsy). The medical community cannot predict who will continue to have seizures and who will not, but they feel that the sooner Epilepsy is diagnosed, the better it can be controlled.

Q: Do non-traditional approaches help?

Some people with Epilepsy have tried many different approaches to improve their seizure control. In some cases, the person feels that they have experienced improvement. However, scientific studies have not been conducted into most non-traditional approaches. Techniques known to reduce stress or improve overall health may be helpful to some people. Other techniques that have been tried are biofeedback, diets, acupuncture, and meditation.

Q: Does transcendental meditation have any effect on Epilepsy?

The medical community has not determined if things such as transcendental meditation have any real effect on Epilepsy. It has been shown that when people know what is happening at a given moment, some can influence the automatic processes of the body. With biofeedback, some people can moderate and possibly change certain functions thought to be involuntary, such as the rhythm of their brain waves, blood pressure, heart rate, etc. The significance of this for Epilepsy is not known.

Q: Does biofeedback help?

Biofeedback is the process of moderating, limiting or changing certain physiological functions previously thought to be involuntary, such as heart rate, blood pressure, brain waves, etc. For Epilepsy, a person could be given extensive biofeedback training and taught behavioural modification techniques through which he/she control certain physiological functions related to seizures. Biofeedback training can also be taught as a method of stress reduction. This in itself can reduce the frequency of seizures in some persons with stress related seizures. Further study is needed to ascertain the value of biofeedback in the treatment of Epilepsy. Non-medical approaches may improve

seizure control in some persons, but should not be undertaken without the knowledge of the physician prescribing the anti-convulsants. Under no circumstances should anti-convulsants be stopped suddenly as this may precipitate prolonged and life-threatening seizures.

Q: Is there a special diet for people with Epilepsy?

Good nutritional habits and a healthy life style may assist in the maintenance of optimum seizure control. Experiencing a drastic weight change may mean that either a chemical or metabolic imbalance is occurring, and you should consult your physician. Though some anti-convulsants may cause nutrient deficiencies in some people, a well balanced diet will usually prevent this. Also see KETOGENIC DIET

Q: What is a ketogenic diet?

A ketogenic diet is very rich in lipids (fats) and oils, but low in proteins and carbohydrates. This unusually high intake of lipids and oils creates a condition in the body know as "ketosis". The metabolic shift that is created increases the seizure threshold for some. This diet is also calory and liquid restricted. The Ketogenic diet is mainly effective in children. It requires careful preparation and strict adherence. Although it takes a significant commitment to be successful, many children have greater seizure control with this diet than with conventional (drug) therapys. Some are able to reduce or eliminate antiseizure medications. Careful medical supervision is essential when using this as a therapy.

Topic: Living with Epilepsy

Q: Can people living with Epilepsy lead normal lives?

Experience has shown that people with Epilepsy have fewer seizures if they lead normal active lives. This means they should be encouraged to find jobs, either full or part-time. People with any disabilities are now protected under amendments to the Human Rights Code (Canada). However, some jobs, because of the nature of technical equipment or machinery, may not be recommended for a person with Epilepsy. It is therefore most important for a young adult to work with the school guidance department to establish appropriate career goals.

Q: What can people with Epilepsy do to help their health?

Like any medical condition, Epilepsy is affected by the general health

and well-being of the person affected. So, anything that can be done to improve the state of the person can have a positive effect on Epilepsy. This includes diet, exercise, rest, reducing stress, avoiding depression, and staying away from alcohol and illegal drugs.

Q: Who should know that I have Epilepsy?

Openness and honesty about Epilepsy is important. A child's teacher should be informed about the type of seizure, what they look like, their frequency, and any first aid requirements. There are advantages and disadvantages to telling an employer. What you tell them may depend upon how comfortable you are discussing your Epilepsy, the kinds of seizures involved, and the type of job. An employer may ask if you have a medical problem that would make you unable to do your job, but they may not ask generally about your medication condition.

Q: Is there prejudice against people with Epilepsy?

While much progress has been made in reducing societal prejudice against Epilepsy, discrimination or rejection may also be a problem for the person with the seizures. In addition, family and friends may be overprotective or impose unnecessary restrictions. In the end, the person with seizures may lose confidence or feel "like a second class citizen".

Q: Are there any problems having children?

Women who use seizure-controlling drugs must be careful when it comes to having children. There have been reported cases of birth defects for these women. While the "normal" rate of birth defects is 2-3% , women with epilepsy who are not taking medication have a slightly higher (1/2%) risk of malformations. Women on a single medication have a risk of about 6-7%, with some differences due to the particular medication involved. Multiple drug combinations drastically increase the risk.

This creates a problem because the drugs may create risks for the baby, but the need for anti-seizure drugs remains during pregnancy. Seizures may even be more frequent during pregnancy, and harm both the baby and the mother.

A doctor may decide to change or reduce a woman's medication if she plans to become pregnant. In some cases, however, the doctor may recommend that the risks of pregnancy are too great for the mother and child. Any changes in medication must be considered carefully, and a woman should never adjust her own medication.

There are some special issues relating to maternal health during

pregnancy for women with Epilepsy, and this may require special attention.

Finally, some seizure medications can lead to failures of oral birth control pills.

Q: Can medications for controlling Epilepsy harm a nursing baby?

Always check with your physician if you are on anticonvulsants and planning to breast feed. Although anticonvulsant medication has been measured in the breast milk of mothers with Epilepsy, the amount is usually too low to harm the child.

Q: Can people living with Epilepsy drive a car?

In Ontario, the situation is that anyone with a history of Epilepsy may drive a motor vehicle, provided the person's physician certifies that he or she has been free from seizures for a minimum period of a year. Each case is reviewed by a medical advisory committee.

The situation may be different in your location. Ask your physician about it, or contact a driver examination centre.

Q: Can people living with Epilepsy go swimming?

It is advised that before a person with Epilepsy goes swimming, they should consult their doctor. When a person with Epilepsy does go swimming, they should not do it alone (common water-safety advice for everyone). It is also recommended that swimming be done in a supervised pool rather than beaches, lakes, or rivers.

Q: Can Epilepsy lead to problems at school?

Longstanding seizure disorders may be associated with seizure-induced brain damage and memory problems. Also, children with Epilepsy may experience learning or concentration problems because of the neurological disorder or the medications.

If a child who has Epilepsy is having problems at school, either academically or socially, the teacher and the principal should be asked to help. If you would like your child to be tested by the school psychologist, arrange it through the principal. If your child is having academic problems, ask to see the Special Education Consultant for the area. In consultation with the child's teacher, a modified program can be arranged if necessary. Children with Epilepsy should be allowed to take part in all regular school activities, including sports.

Q: Can Epilepsy cause emotional problems?

People with Epilepsy may develop depression for both biological and social reasons. Some longstanding poorly controlled seizure disorders may be associated with chronic personality changes. Also, or short durations following temporal lobe seizures some patients may have emotional "swings" or other thinking difficulties.

While Epilepsy is a medical problem, the person with the seizures must also make a number of emotional adjustments. The first challenge is acceptance of the diagnosis. Initially people with Epilepsy and their families may experience shock or denial. Anger, fear, and depression are also common. However, with information and support, people with Epilepsy can understand the condition and develop positive coping strategies.

Q: Can Epilepsy lead to problems with self-esteem?

It is important to remember that people with Epilepsy can, and do, live full, productive lives. If self-esteem becomes a problem, open discussion with supportive friends, family, or a professional counsellor can help you develop new ways of coping and a new sense of hope.

Topic: Working With Epilepsy

Q: What occupations are not appropriate for people with Epilepsy?

Given that they are trained with appropriate sets of skills and/or education, the vast majority of people with Epilepsy are capable of performing any job. Some exceptions to the rule are: occupations in the military, commercial airlines, and fire brigade as the lives of others may be endangered should a seizure occur. Consideration should be give to the type of seizures and how well they are controlled by medication.

Q: Can people with Epilepsy fly a plane?

Persons with Epilepsy may not be able to fly a plane. There are strict standards that must be met by anyone wanting to get their pilot's license. Each person is individually assessed and must meet a regime of standards set up by the Civil Aviation Medical Centre.

Q: Is there a problem with job safety?

Employers hiring someone with Epilepsy are often concerned that job safety will be compromised in the event of an injury caused by a seizure in the workplace. One study revealed that the accident rate of workers with Epilepsy was lower than those employees without disabilities. Liability is not a factor as long as the employee has been placed in an appropriate job and reasonable accommodation is provided as necessary.

Q: Can an employer ask about Epilepsy on a job application?

Under the Ontario Human Rights Code (Chapter 53, Section 22(2)), it is illegal for an employer to ask about medical problems on the application form. A person with Epilepsy (or any other health problem) is not required to respond to any medical related question. A copy of the Ontario Human Rights Code and A Guide to the Ontario Human Rights Code is available by calling Access Ontario at (613) 238-3630.

Q: Can an employer ask about Epilepsy during a job interview?

In the Ontario Human Rights Codes (Chapter 53, Section 22(3)), nothing precludes the interviewer from asking questions about your health status, however it MUST relate to your ability to perform the essential duties of the job. They may ask "Do you have any medical problems that would make you unable to do the job?", but they MAY NOT ask "Do you have any medical problems?" A copy of the Ontario Human Rights Code and A Guide to the Ontario Human Rights Code is available by calling Access Ontario at (613) 238-3630

Q: Can I be fired because I have Epilepsy?

The Ontario Human Rights Code does not permit employers to fire an employee because they had a seizure at work, or have Epilepsy. Before a person is dismissed, the employer must show that "reasonable accommodation" (Chapter 53, Section 23(2)) has been made to help the person keep their job. Accommodations are determined by doing a physical demands analysis, which is a breakdown of the exact physical requirements necessary to perform the job. Access Ontario, at (613) 232-0489, will be able to provide you with more Ontario Human Rights Information.

Q: Can people with Epilepsy get social assistance?

A person who has Epilepsy may qualify for assistance to prepare for and to obtain employment under the Ontario Ministry of Community and Social Services' Vocational Rehabilitation Services Program. Assistance may take the form of vocational assessment, counselling, academic, or

technical training or job placement. Application should be made to the nearest office of the Ontario Ministry of Community and Social Services, listed in the blue pages in the telephone directory.

A person who is severely disabled by seizures, and unable to compete in the work force, may apply for assistance under Ontario's Benefits Program, often called GAINS-D. Application should be made to the nearest office of the Ontario Ministry of Community and Social Services, listed in the Government of Ontario section of the blue pages on the telephone directory.

Two other kinds of financial assistance are available in Ontario, depending on a person's income: General Assistance, usually referred to as welfare, is available for anyone in urgent need of financial aid. Special Assistance is for a person who is employed, but has extraordinary needs such as a high prescription drug costs. Application for each of these assistance programs should be made through the municipal social service department.

Topic: Epilepsy and Other Disorders

Q: Is Epilepsy related to other neurological problems?

Epilepsy is not necessarily associated with other neurological problems or learning disabilities. Occasionally, the source of the seizures may be reflected in other neurological deficits. Also, medication for seizures may cause sedations and thus decrease the rate of learning. People with Epilepsy have the same range of intelligence as the general population.

Q: Is Epilepsy related to mental illness?

Epilepsy is not related to mental illness. Because of the involvement of the brain, Epilepsy has been mistakenly associated with psychiatric disorders. Epilepsy differs from psychiatric disorders in that seizures last for very brief periods and begin and end abruptly. Further, when not having seizures, people with Epilepsy need not have any changes in their mood or behaviour.

Q: Can Epilepsy affect intelligence?

Seizures can affect intelligence, so prompt diagnosis and rapid control of seizures is important. There is also a risk if seizures are prolonged and there is a significant reduction in oxygen in the brain during seizures. However, these are extremely rare occurrences. In the

case of developmentally delayed persons with Epilepsy, it is most likely that the cause of the developmental delay is also the cause of the seizures. In most cases, people with Epilepsy have normal intelligence.

Q: Is there a link between memory loss and Epilepsy?

Some people with Epilepsy do experience a difficulty in recalling distant and recent events. Often, this is caused by the medications used to treat Epilepsy, or by regular seizure activity. People affected in this way can learn to compensate by using lists and reminders, and by creating an organized environment.

Q: Is Epilepsy related to asthma?

Asthma occurs in children with Epilepsy at about the same frequency as it occurs in the general population. Likewise, the reverse is also true. The drug theophylline can trigger seizures.

Q: Are there any diseases that persons with Epilepsy more prone to?

People with Epilepsy who are on medications may experience side effects that makes them more susceptible to other diseases and disorders. One common condition is Hyperplaxia, an over-growth of the gums caused by the drug Dilantin. Other common problems are liver dysfunction and depression.

Topic: Miscellaneous

Q: Do animals get Epilepsy?

Epilepsy can occur in animals. Like humans, Epilepsy in animals is really just abnormal electrical activity in the brain.

Q: Can dogs sense a seizure in humans before it strikes?

It is possible that some dogs are able to detect pre-seizure changes in the physiology of some people with Epilepsy before the person becomes aware of them. In many cases, the person with Epilepsy is aware of an aura before the onset of the main part of the seizure.

Not enough is known about how dogs can detect seizures before their onset to know exactly what sense(s) are involved in this detection. However, one might hypothesize that since dogs can detect chemical

changes due to fear, seizures that are preceded by a sense of fear might also produce detectable changes.

Topic: More Information

Q: Where can I get more information about Epilepsy?

There are a number of information sources about Epilepsy. Here is a partial list, and I welcome suggestions for other things to be added here.

- o Epilepsy (Ontario) Ottawa-Carleton
B3-180 Metcalfe St.
Ottawa, Ontario, Canada
K2P 1P5
(613) 594-9255
WWW:
<http://www.ncf.carleton.ca/freeport/social.services/epilepsy/menu>
- o Epilepsy Ontario
1 Promenade Circle, Suite 308
Thornhill, ON
M4J 4P8
Telephone: (416) 229-2291 or (905) 764-5099 or (800) 463-1119
E-Mail: epilepsy@epilepsy.org
WWW: <http://www.epilepsy.org>
- o Epilepsy Canada
1470 Peel St., Suite 745
Montreal, Quebec, Canada
H3A 1T1
(514) 845-7866
WWW: <http://www.generation.net/~epilepsy>
- o Epilepsy Foundation of America (EFA)
8000 Corporate Drive, Suite 120
Landover, MD 20785
1-800-225-6872 or 1-800-EFA-1000
E-mail: ntsa@aol.com
WWW: <http://www.efa.org/>
- o National Institute of Health
1-800-352-9424

- o Additional information on the Ketogenic diet can be obtained from: The Johns Hopkins Pediatric Epilepsy Center, (410)955-9100 or The Charlie Foundation to Help Cure Pediatric Epilepsy, (800)FOR-KETO.
- o A support group for patients with Rasmussen's encephalitis, a form of Epilepsy characterized by intractable seizures, eventual hemiplegia and dementia, is being started. Interested people should contact:

Joan MacKeigan <macmarwa@cam.org>
380 Raymond St.
Saint Bruno, QC
Canada
J3V 2S7
514-461-2586

- o In many areas there are local associations that may be valuable to you.

Q: What books are available on Epilepsy?

- o EPILEPSY AND THE FAMILY by Richard Lechtenberg. Harvard Univ. Press, 79 Garden Ave, Cambridge, MA 02138-1311
- o LIVING WELL WITH EPILEPSY by Robert J. Gumnit, Demos Publications, 1990, 156 Fiftth Ave, NY, NY 10010
- o EPILEPSY AND YOU, by Frank O. Volle and Patricia A. Heron
- o DOES YOUR CHILD HAVE EPILEPSY? by J.E. Jan, R.G. Ziegler, G. Erba, Austin PRO-ED Press, 5341 Industrial Oacks Blvd, Austin, TX 78735
- o CHILDREN WITH EPILEPSY: A PARENTS GUIDE, by Helen Reisner, Woodbine House, 5615 Fishers Lane, Rockville, MD 20852
- o ONE MIRACLE AT A TIME, HOW TO GET HELP FOR YOUR DISABLED CHILD - FROM THE EXPERIENCE OF OTHER PARENTS, by Irving Dickman, PACER Center, Inc 4826 Chicago Ave, Minneapolis, MN 55417
- o THE EPISODE, by Richard Pollak * This one is listed as fiction
- o HAVING EPILEPSY, THE EXPERIENCE AND CONTROL OF ILLNESS by Joseph Schneider and Peter Conrad, Temple Univ Press, Broad and Oxford Streets, Philadelphia, PA
- o PSYCHOPATHOLOGY IN EPILEPSY, SOCIAL DIMENSIONS by Steven Whitman

and Bruce Hermann, Oxford University Press, 16-00 Pollitt Drive, Fair Lawn, NJ 07419-2799

- SEIZURES AND EPILEPSY IN CHILDHOOD: A GUIDE FOR PARENTS by John Freeman, EileenVining and Diana Pillas, The John Hopkins University Press, 701 West 40th St, Balitimore, MD 21211
- A GUIDE TO UNDERSTANDING AND LIVING WITH EPILEPSY, Orrin Devinsky, F.A. Davis Company, 1915 Arch Street, Philadelphia, PA 19103
- BRAINSTORMS: EPILEPSY IN OUR WORDS, by Steven Schachter, Raven Press 1185 Avenue of the Americans, NY, NY 10036
- THE BRAINSTORMS COMPANION: EPILEPSY IN OUR VIEW, by Steven Schachter, Raven Press, 1185 Avenue of the Americas, NY, NY 10036
- THE EPILEPSY DIET TREATMENT: AN INTRODUCTION TO THE KETOGENIC DIET (Demos Press, 1994) by John Freeman, Millicent Kelly, and Jennifer Freeman
- CHALLENGE OF EPILEPSY by Sally Fletcher (Aura Publishing Company/20 Sunnyside Ave., #A150/Mill Valley, CA 94941)

Q: Where can I find information on the Internet about Epilepsy?

- There are two Epilepsy-related mailing lists: "Epilepsy-List" is intended for general discussions about Epilepsy and seizure disorders. Most traffic is from people living with Epilepsy or their friends and family. The companion list, "Epilepsy-PRO" is intended for discussions about Epilepsy and seizure disorders by professionals working in this field. To find out about these lists, send mail to listserv@calvin.dgbt.doc.ca and include the command lines "info epilepsy-list" and/or "info epilepsy-pro".
- There is an Epilepsy Home Page on the web that has several links, including one for the Ketogenic Diet. The URL is <http://www.swcp.com/~djf/epilepsy/index.html>. The Ketogenic Diet link shows the URL <http://www.swcp.com/~djf/epilepsy/ketogenic.html>.
- Mass General Hospital and Harvard sponsor a neuro forum where people can ask questions about seizure disorders, meds, etc. The address is <http://dem0nmac.mgh.harvard.edu/neurowebforum> and you may try <http://dem0nmac.mgh.harvard.edu/epilepsy/epihome.html>. [Note: that is a "zero" in the hostname: dem0nmac. -- ASP]

- o Another source of information is
<http://www.webcom.com/pleasant/sarah/epilepsy.html>
- o The Charles A. Dana foundation, which has opened a website at
<http://www.dana.org/>, supports brain research and school reform by means of grants and public education initiatives.
- o There's a fairly extensive description of Depakote at
<http://www.fairlite.com/ocd/medications/depakote.shtml> and this may be a good reference for information on many medications:
<http://www.fairlite.com/ocd/medications>.

Another reference for drug information is also available:
http://pharminfo.com/drugdb/db_mnu.html .

- o Canine Epilepsy:
http://www.zmall.com/pet_talk/dog-faqs/epilepsy.html
- o The Epilepsy Society of Northwest Florida has a home page:
<http://www.cil.gulf.net/epil.html>.
- o The Epilepsy Association of Metro Toronto also has a home page:
<http://www.interlog.com/~rutheamt>.
- o Your Child and Neurosurgery contains several chapters on the surgical treatment of children with medically refractory epilepsy:
<http://peds-neuro-web.med.nyu.edu>.
- o Other sites people have mentioned:
 - + Epilepsy Support/Education Organizations:
<http://neurosurgery.mgh.harvard.edu/ep-resrc.htm>
 - + MGH Epilepsy Surgery:
<http://neurosurgery.mgh.harvard.edu/epilepsy.htm>
 - + Assorted Medical Links:
<http://soho.ios.com/~lewycky/medical.html>
 - + SURGERY FOR EPILEPSY:
<http://neurosurgery.mgh.harvard.edu/epil-nih.htm>
 - + <http://ccfadm.eeg.ccf.org/~tom/> cv.out
 - + AECOM/MMC Epilepsy Home Page:
<http://balrog.aecom.yu.edu/epilepsy/>
 - + Neurosciences Internet Resource Guide:
<http://http2.sils.umich.edu/Public/nirg/nirg1.html>
 - + Department of Neurological Surgery: <http://www.neus.ccf.org/>
 - + MCG-Neurology: <http://www.neuro.mcg.edu/>
 - + University Medical Center:
<http://www.ahsc.arizona.edu/umc.shtml>

- + Tammi's Epilepsy Page:
<http://www.mndly.umn.edu/~chur/epilepsy.html>
- + JHMI-InfoNet: Patient Advocacy Groups:
<http://infonet.welch.jhu.edu/advocacy.html>
- + Neurology/Neuroscience:
<http://www.informatik.uni-rostock.de/HUM-MOLGEN/neurology/>
- + Yale Section of Neurosurgery:
<http://info.med.yale.edu/surgery/neurosurg/>
- + UNM Neurosurgery Associates:
<http://spine.unm.edu/neurosurg/fac&res.html>
- + Basic Sciences: <http://lnbd.uicomp.uic.edu/homepage/bs.htm>
- + PSI PET Program: <http://pss023.psi.ch/>
- + About the CVRC: <http://ceres.med.upenn.edu/www/cvrc.html>
- + <http://www.med.stanford.edu/touchstone/listserv.html>
- + <ftp://ftp.win-uk.net/pub/users/copernic/medical.resources>
- + <http://www.ibmpcug.co.uk/~copernic/meda.htm>
- + Neuropsychology Central:
<http://www.premier.net/~cogito/neuropsych.html>
- + EpiNet: <http://www.epinet.org.au/>

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Send corrections/additions to the FAQ Maintainer:
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