## AND SEIZURES DISORDERS: EPILEPSY 101

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## 1. WELCOME

**INTRODUCTION** 

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Epilepsy can be a scary diagnosis, but gathering knowledge so that you understand it better can empower you to live a full and happy life with this condition."

#### Famous People with Epilepsy

- Bud Abbott
- Rondé Barber
- Tiki Barber
- Richard Burton
- Julius Caesar
- Lewis Carroll
- Fyodor Dostoevsky
- George Gershwin
- Danny Glover

- Florence Griffith Joyner
- Lil' Wayne
- Napoleon I
- Edgar Allan Poe
- Prince
- Theodore Roosevelt
- Socrates
- Harriet Tubman
- Vincent van Gogh
- Neil Young

#### **STATISTICS**

1 in 10 people will experience a seizure in their lifetime.

1 in 100 people will develop epilepsy.

Almost 500 new cases of epilepsy are diagnosed every day in the United States.

#### **STATISTICS**

Epilepsy affects over 3 million Americans of all ages.

It impacts more than multiple sclerosis, cerebral palsy, muscular dystrophy, and Parkinson's disease combined.

In America, epilepsy is as common as breast cancer and takes as many lives.

#### **STATISTICS**

Epilepsy results in an estimated annual cost of \$15.5 billion in medical costs and lost or reduced earnings.

Historically, epilepsy research has been underfunded. Each year the National Institute of Health spends \$30 billion on medical research, but just ½ of 1% of that is spent on epilepsy.

# 2. EPILEPSY? SEIZURES?

FROM THE BEGINNING

#### WHAT IS EPILEPSY?

- ► Epilepsy is a seizure disorder.
- A person with epilepsy has had two or more unprovoked seizures, regardless of seizure type.
- The seizures may result from a hereditary tendency or a brain injury, but often the cause in unknown.

#### **CAUSES OF EPILEPSY**

Epilepsy can develop at any age.

Epilepsy has no identifiable cause in about half of those who have the condition.

In the other half, it may be traced to various factors: Genetic Influence

**Developmental Disorders** 

Prenatal Injury

Head Trauma

Medical Disorders

Dementia

Diseases

Calcium Channelopathies

High fevers

#### WHAT IS A SEIZURE?

A seizure occurs when neurons in the brain create abnormally increased electrical activity that temporarily interrupts normal electrical brain function.

#### Generalized Seizure

If the seizure spreads through the entire brain, many brain functions may be involved.

### Partial (Focal) Seizure

If electrical activity is localized or isolated to a specific area of the brain. That is called a focal seizure.

#### **GENERALIZED SEIZURES**

Generalized seizures appear to start in all parts of the brain simultaneously and have no identifiable onset.

Many generalized seizures start and spread so quickly it is impossible to identify the source.

#### **TYPES OF GENERALIZED SEIZURES**

- Tonic seizures
- Clonic seizures
- Tonic-clonic seizures (formerly known as grand mal seizures)
- Absence seizures (formerly known as petit mal seizures)
- Myoclonic seizures
- Atonic seizures

#### **TONIC SEIZURES / TONIC PHASE**

- The person's muscles initially stiffen and they lose consciousness.
- ► The person's eyes roll back into their head as their muscles contract and the back arches.
- As the chest muscles tighten, it may become harder for the person to breathe. The lips and face may take on a bluish hue, and the person may begin to make gargling noises.
- Many observers have the misconception that the person is in danger of "swallowing their tongue," so they attempt to put something in the person's mouth.

#### **CLONIC SEIZURES / CLONIC PHASE**

- During a clonic seizure, a person's muscles begin to spasm and jerk.
- The elbows, legs and head will flex, and then relax rapidly at first, but then the frequency of the spasms will gradually subside until they cease altogether.
- It is common for a person to let out a deep sigh, after which normal breathing resumes.

#### **TONIC-CLONIC SEIZURES**

A tonic-clonic seizure is a phase of a tonic seizure followed by a phase of a clonic seizure. After a person transitions from the tonic to the clonic phase and to the post-seizure period, they'll likely remain unconscious for a few minutes or more, depending on the severity of the seizure.

During this time, the brain is extremely active trying to stop the cells from firing to bring the seizure under control.

#### **ABSENCE SEIZURES**

- An absence seizure is a very uncommon seizure that begins suddenly and occurs without any warning signs.
- People experiencing absence seizures typically appear to stare without moving.
- Usually lasting less than 15 seconds, absence seizures can occur ma times a day and may be mistaken for day-dreaming.
- While the people may not remember what happened during the seizure, they'll typically return to alertness as soon as the seizure is finished.

#### **MYOCLONIC SEIZURES**

- Myoclonic seizures result in an increase in muscle tone.
- Patients having myoclonic seizures typically react as if hit from a single jolt of electricity.
- Any part of the body may stiffen, giving a rapid jerking motion.
- The area of the brain stem responsible for increasing and decreasing muscle tone are close together- meaning atonic and myoclonic seizures probably begin in the same place.

#### **ATONIC SEIZURES**

Also known as drop attacks or drop seizures.

- Atonic seizures cause the muscles to go limp.
- The patient's body may slump or crumple to the ground, possibly causing injury.

#### **TYPES OF PARTIAL SEIZURES**

There are two types of partial seizures.

Complex partial seizures
-consciousness is
impaired or lost

Simple partial seizures
-consciousness is retained

By observing which area of the body is affected by the seizure, doctors can identify where in the brain the seizure occurred.

### POSSIBLE SYMPTOMS OF COMPLEX PARTIAL SEIZURES

- Last 1 to 2 minutes
- May have an aura
- Automatisms (such as lip smacking, picking at clothes, fumbling Unaware of environment
- May wander
- May have amnesia of seizure events
- Mild to moderate confusion during
- Sleepy afterward

#### SIMPLE PARTIAL SEIZURES

- Seizure occurs in one area of the brain. May spread to other areas.
- Consciousness is not lost during a simple partial seizure.
- Doctors typically organize them into four areas, depending on the location in the brain and parts of body affected.
- Motor, Sensory, Autonomic, Psychic

#### **MOTOR SIMPLE PARTIAL SEIZURES**

A simple partial seizure with motor symptoms will affect muscle activity, causing jerking movements of the foot, face, arm, or other part of the body.

#### **SENSORY SIMPLE PARTIAL SEIZURES**

A simple partial seizure with sensory symptoms affect the senses.

For example: hearing, seeing, feeling, tasting, smelling things that are not there. Possible hallucinations, and other distortions.

#### **AUTONOMIC SIMPLE PARTIAL SEIZURES**

A simple partial seizure with autonomic symptoms affects the part of the brain responsible for involuntary functions.

It may cause changes in blood pressure, heart rhythm, bowel function, etc. One rare type of autonomic simple partial seizures is **abdominal epilepsy**, which can cause projectile vomiting, severe abdominal pain and cramping.

#### **PSYCHIC SIMPLE PARTIAL SEIZURES**

A simple partial seizure with psychic symptoms affects parts of the brain that trigger emotions or previous experiences.

It may cause feelings of fear, anxiety, joy, déjà vu, jamais vu, etc.

#### **MULTI-SEIZURE TYPES & MORPHING**

People can have more than one seizure type.

The type of seizures that people can have can also change. This is called morphing.

Examples: partial to generalized, generalized to partial (rare), two types of partial, two types of generalized, etc.

#### **REFLEX EPILEPSIES**

- Reflex Epilepsies are a group of epilepsies in which seizures are brought on by a certain stimulus.
- A stimulus could be a sound, type of light, an action (like reading), or even thinking about a topic.

Example: Photosensitive epilepsy

#### **AURAS**

An aura is a distinctive feeling or some other indication that a seizure is about to occur.

Auras vary significantly between different people.

 Not every person with epilepsy will experience an aura before a seizure.

## **3.**

EPILEPSY AND
Co-Existing
Disorders

#### **CO-EXISTING DISORDERS**

- Developmental Disorders (Autism)
- Metabolic Disorders
- Migraines
- Pulmonary Disorders
- Renal Disorders
- Sleep Disorders
- ► Infantile Spasms
- Lennox- Gastaut Syndrome

## HEADACHES/MIGRAINES AND EPILEPSY

- Ictal headaches are headaches that occur before or after a seizure. Or in rare occurrences during a seizure.
- People with epilepsy have a higher risk for migraines.
- A new study showed a genetic link between epilepsy and migraines.
- People with a strong family history of epilepsy have a strong risk factor for migraines.

#### **CEREBRAL PALSY AND EPILEPSY**

Epilepsy is common in people with cerebral palsy.

This is because people with cerebral palsy often have brain injury. This brain injury makes it easy for seizures to occur.

#### **HYDROCEPHALUS AND EPILEPSY**

Seizures are <u>not</u> a common occurrence for people with hydrocephalus.

Epilepsy is often associated with shunt-treated hydrocephalus.

Studies have shown that the most likely reason for the development of epilepsy associated with hydrocephalus is malformations of the cerebral cortex.

#### **AUTISM AND EPILEPSY**

New research has shown that adults with epilepsy are more likely to have a greater number of characteristics of autism and Asperger's.

The scientists found that seizures interfere with neurological function that affects social functioning in the brain-causing the similar characteristics to autism.

#### **AUTISM AND EPILEPSY**

It is estimated that as many as 1/3 of individuals with an autism spectrum disorder also have epilepsy.

Experts propose that some of the brain abnormalities associated with autism may contribute to seizures.

### **AUTISM AND EPILEPSY**

Silently Seizing by Caren Haines, R.N. discusses unrecognized seizures and their damaging impact on individuals on the autism spectrum.

Many children with autism do not receive effective treatment because the epilepsy element is not addressed.

Measurable gains have been seen for children when treated early for epilepsy.

### **MOOD DISORDERS AND EPILEPSY**

Epilepsy and mood disorders appear to share a common neurobiology.

 Interictal dysphoric disorder (IDD) is a mood disorder found found in people with epilepsy.

Characteristic of IDD is having at least three of eight of the following symptoms between seizures: depression, anergia, pain, insomnia, fear, anxiety, paroxysmal irritability, euphoric mood

#### **DEPRESSION AND EPILEPSY**

- People with epilepsy may be more likely than other people to experience emotional changes.
- Depression and mood changes can occur before, during, or after a seizure.
- People with a history of depression have a 3 to 7 times higher risk of developing epilepsy.
- ► There is a higher incidence of depression in people with epilepsy than in the general population or in individuals with other chronic conditions, such as diabetes.

# **COGNITION AND EPILEPSY**

Cognitive impairment can be associated with chronic epilepsy.

In adults this can include mental slowness, memory difficulties, and attention deficits.

In children this include language problems, learning difficulties, poor academic outcome, and behavior problems.

### **WOMEN AND EPILEPSY**

The hormones estrogen and progesterone may influence seizure occurrence in women.

Catamenial epilepsy: type of epilepsy that has tendency for increased seizures related to the menstrual cycle.

#### **EPILEPSY AND PREGNANCY**

Epilepsy and Fertility - Important to Know

It's possible that having epilepsy may make it more difficult to get pregnant.

Women with epilepsy have fewer children than women in general. Their fertility rate is between 25% and 33% lower than average.

Here are some possible reasons why:

- \* Women with epilepsy have higher rates of some conditions that can cause infertility. One of these is polycystic ovarian syndrome (PCOS).
- \* Women with epilepsy are more likely to have irregular menstrual cycles, which can make it more difficult to get pregnant.
- \* Women with epilepsy are also more likely to have menstrual cycles that do not produce an egg. These are called anovulatory cycles.
- \* Women with epilepsy are also more likely to have abnormalities in hormones involved in pregnancy.

#### **EPILEPSY AND PREGNANCY**

Planning ahead for pregnancy is important:

Some anti-seizure medications can cause risk to the fetus, as can seizures themselves.

It is important to work with your doctor to determine a plan of treatment for pregnancy before you get pregnant.

There are no anti-seizure drugs that are 100% without risk of causing birth defects. But some anti-seizure medications appear to better than others. Here's what doctors know so far:

Depakete and Depakene seem to carry the highest risk of damage to the baby.

Other medications with high risks include: Phenobarbital, Dilantin (Phenytoin), Depakote (Valproic Acid), Tegretol (Carbamazepine and Carbatrol).

Lamictal can also cause breakthrough seizures during pregnancy.

The best rule is to use the single medicine that is most effective in treating your seizures, but with some bias toward the newer FDA category C antiepileptic drugs such as:
Neurontin, Topamax, Zonegran,
Trileptal, Keppra, Lyrica and Vimpat.

#### **MORTALITY AND EPILEPSY**

- Epilepsy occasionally can be fatal.
- This uncomfortable truth often is hidden or ignored because it is relatively rare and so hard to discuss.
- Overall, epilepsy increases the risk of dying by between 1.6 and 3 times that of the general population.
- Types of Conditions Causing Increased Mortality in Epilepsy
- 1. Ordinary mortality from usual causes of death.
  - 2. Death due to the illness that is causing the epilepsy.
  - 3. Death from associated conditions, such as depression.
  - 4. Trauma or drowning from seizures.
  - 5. SUDEP: Sudden Unexpected Death in Epilepsy

# THE EPILEPSY PIPELINE COMMUNITY CONFERENCE

- A conference sponsored by the Epilepsy Foundation held once a year to discuss new treatments, devices, therapies, and much more.
- The 2018 Conference was held in San Francisco, CA in February. No Pipeline Conference was held in 2017, but the Antiepileptic Drug Trials XIV Conference was held in its place.
- They post the information from the conference online. http://www.epilepsy.com/accelerating-new-therapies/2016-epile psy-pipeline-conference

# RESEARCH ON NEW TREATMENTS FOR EPILEPSY

- Medical Cannabis- Cannabidiol
- New medication for drug-resistant epilepsy
- Surgery separating the posterior quadrant of the brain
- Transcranial Magnetic Stimulation (TMS)
- EEG Patch to track seizure

#### **GENETIC TESTING FOR EPILEPSY**

- Helpful for anyone with a suspected genetic cause of epilepsy.
- Genetic testing in a person with epilepsy can help confirm a specific diagnosis. It may also give information about associated neurological or medical conditions that may arise over time.
- It may assist your neurologist with selecting an appropriate seizure medication and also expectations with expectations regarding appropriate seizure control. Genetic information can also influence if a special diet can help with seizure control.

# **GENETIC TESTING FOR EPILEPSY**

 Genetic information may help to limit invasive or unnecessary testing.

Genetic testing may assist with understanding the prognosis or outlook of a person's epilepsy and provide a basis for further genetic counseling for families.

# **NEW DEVICES FOR EPILEPSY**

- Smart Watch by Smart Monitor <a href="http://smart-monitor.com/">http://smart-monitor.com/</a>
- Visualase by Medtronic <a href="http://www.medtronic.com/for-healthcare-professionals/products-thera-pies/neurological/laser-ablation/visualase/">http://www.medtronic.com/for-healthcare-professionals/products-thera-pies/neurological/laser-ablation/visualase/</a>
- SAMi Sleep Activity Monitor by HiPass Designs <u>http://www.samialert.com/</u>
- Monarch eTNS From Neurosigma <a href="http://www.monarch-etns.com/">http://www.monarch-etns.com/</a>
- ► Embrace from Empatica <a href="https://www.empatica.com/product-embrace">https://www.empatica.com/product-embrace</a>
- Helpful app for keeping track of seizures: TrackIt https://www.seizuretracker.com/

# 4. EPILEPSY AND THE LAW

WHAT ARE YOUR RIGHTS?

## **EDUCATION AND EPILEPSY**

Schools are required by law to provide accommodations and supports for students with epilepsy when needed. 504 Plans can provide accommodations that allow students to access all aspects of their education.

Under the Individuals with Disabilities in Education Act (IDEA), IEPs may be granted to students from pre-K to grade 12, usually under an OHI eligibility, to provide services and accommodations for students whose epilepsy impacts their education.

# EXAMPLES OF ACCOMMODATIONS AND SERVICES FOR STUDENTS WITH EPILEPSY

- Individualized Healthcare Plan: detailed plan for school staff and school nurse to assist student during seizures and handle other medical effects of epilepsy at school.
- Supervision to assist with moving around school safely.
- Allowing assistance animals in the school.
- Specialized instruction to address cognitive effects of epilepsy and anti-epileptic drugs.
- Adjusted schedule to reduce stress and exhaustion from medication or seizure activity.

## HIGHER EDUCATION AND EPILEPSY

The IDEA does not cover students in university or post-high school work, but Section 504 and the ADA do.

Students in higher education may obtain accommodations by making their school and instructors aware of their epilepsy, providing medical documentation, and specifically requesting accommodations in each class where it is needed.

Most colleges/universities have ADA offices that help coordinate accommodations.

### DISCRIMINATION

The Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act, and the Fair Housing Act protect individuals with epilepsy from discrimination on the basis of their disability.

This covers discrimination in the school, in the workplace, in government services, in housing, and in public accommodations (public businesses).

# **EPILEPSY IN THE WORKPLACE**

- Workers with epilepsy are entitled by law to request accommodations that will enable them to perform their job.
  - They must be <u>otherwise qualified</u> for the job.
  - The requested accommodation must be <u>reasonable</u>.
  - The accommodation <u>must not cause undue burden</u> on the employer.

#### **EPILEPSY IN THE WORKPLACE**

Interview
questions must be
related in some
way to the ability of
the candidate to
perform the job.

Applicants/Employe es do not have to disclose their diagnosis <u>unless</u> they are using it as the basis to request an accommodation. There are pros and cons to disclosing and to keeping your condition secret.

#### **Confidentiality:**

Employers must keep employee health information that is disclosed confidential and only make it available to staff who need to know.

# EXAMPLES OF WORKPLACE ACCOMMODATIONS FOR EPILEPSY

- Adjusted work schedule to prevent fatigue.
- Avoiding the use of ladders, tasks involving climbing, etc. when those are not major job duties for the position.
- Providing a checklist for tasks.
- Bringing an assistance animal to work.
- Providing transportation to off-site meetings if the employee cannot drive.

# 5. LIVING WITH EPILEPSY

#### TRIGGERS OR WHAT TO AVOID

- Sleep Deprivation
- Missing Medication
- Alcohol
- Antihistamines and Decongestants
- Caffeine
- Stress
- Some Antibiotics and herbal supplements
- Strobe Lights

Keeping a journal to identify triggers can be helpful

# SO YOU THINK YOU OR SOMEONE YOU KNOW IS HAVING SEIZURES, BUT HAVEN'T BEEN DIAGNOSED...WHAT'S NEXT?

- Document when you observe the seizure/spell.
- What is happening? What are you observing?
- Trust your gut
- Be vigilant
- Be persistent. If your doctor cannot answer your questions about what is happening and why, seek a second or third opinion.

## **LIVING WITH EPILEPSY**

- Dealing with lack of public knowledge/stigma
- Establishing routines and learning to avoid triggers
- Dealing with the side effects of epilepsy treatments
- Adaptations and coping mechanisms for some of the limitations

# **EPILEPSY ORGANIZATIONS**

- Epilepsy Foundation
- Epilepsy Foundation: Florida
- Epilepsy Association of Central Florida
- CURE: Citizens United for Research in Epilepsy
- ► FACES: Finding a Cure for Epilepsy and Seizures
- Epilepsy Society-UK

# **RESOURCE WEBSITES**

- http://www.epilepsy.com/
- http://epilepsyu.com/
- http://www.epilepsysociety.org.uk/
- Epilepsy Foundation of Florida, <a href="http://www.efof.org/">http://www.efof.org/</a>
- The Anti-Epilepsy Drug Registry, <a href="http://www2.massgeneral.org/aed/">http://www2.massgeneral.org/aed/</a>
- EEOC page on Epilepsy in the Workplace, http://www.eeoc.gov/facts/epilepsy.html

#### MORE RESOURCE WEBSITES

- Different Brains, <a href="http://differentbrains.org/">http://differentbrains.org/epilepsy-pregnancy-with-kimberley-spire-oh-edb-126/</a>
- ► Florida Association of Special Education Attorneys,

  <a href="https://www.facebook.com/Florida-Association-of-Specia">https://www.facebook.com/Florida-Association-of-Specia</a>

  <a href="li-Education-Attorneys-195577053816539/">l-Education-Attorneys-195577053816539/</a>
- Disability Rights Bar Association, http://disabilityrights-law.org/
- Job Accommodation Network, <a href="https://askjan.org/">https://askjan.org/</a>

#### **CITATIONS**

What is a Seizure?

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http://www.youtube.com/watch?v=3QLkgA08eIc

What is Epilepsy?

http://epilepsy.med.nyu.edu/epilepsy/what-epilepsy

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Causes of Epilepsy

http://www.mavoclinic.com/health/epilepsv/DS00342/DSECTION=causes

First Person Language for Epilepsy

http://www.fddc.org/sites/default/files/file/about/People%20First%20Language.pdf

Statistics

http://www.epilepsy.com/node/986825

http://www.cdc.gov/epilepsy/basics/fast\_facts.htm

http://www.epilepsvfoundation.org/aboutepilepsv/whatisepilepsv/statistics.cfm

Types of Seizures

http://www.epilepsywarriors.org/epilepsy-warriors-library/40-different-types-of-seizures/

http://professionals.epilepsy.com/wi/print\_section.php?section=seizures\_classified

http://neurology.stanford.edu/divisions/e\_02.html

http://stason.org/TULARC/health/epilepsy/11-What-is-the-difference-between-partial-and-general-seizur.html#.UZ50vWRATOw

Auras

http://www.epilepsy.com/epilepsy/auras

Generalized Seizures

http://www.hopkinsmedicine.org/neurology\_neurosurgery/specialty\_areas/epilepsy/seizures/types/generalized-seizures.html

Types of Generalized Seizures

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Tonic Seizures

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Clonic Seizures

 $http://www.hopkinsmedicine.org/neurology\_neurosurgery/specialty\_areas/epilepsy/seizures/types/tonic-and-clonic-seizures.html$ 

Tonic-Clonic Seizures

 $http://www.hopkinsmedicine.org/neurology\_neurosurgery/specialty\_areas/epilepsy/seizures/types/tonic-clonic-grand-mal-seizures.html$ 

#### Atonic Seizures

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#### Mvoclonic Seizures

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#### Absence Seizures

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#### Partial Seizures

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#### Types of Partial Seizures

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#### Complex Partial Seizures

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#### Simple Partial Seizures

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#### Multi-Seizure types & Morphing

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#### Reflex Epilepsies

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#### Co-existing Disorders

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http://www.ninds.nih.gov/disorders/infantilespasms/infantilespasms.htm

#### Women and Epilepsy

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Headaches & Migraines and Epilepsy

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Cerebral Palsy and Epilepsy

Children with Cerebral Palsy: A Parent's Guide by Elaine Gerllis

Hydrocephalus and Epilepsy

http://www.hydroassoc.org/ha-updates/seizures-and-hydrocephalus/

Autism and Epilepsy

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Mood Disorders and Epilepsy

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Cognition and Epilepsy

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http://www.medicalnewstoday.com/releases/276400.php

Triggers or What to Avoid

Orlando Epilepsy Center

http://www.epilepsyfoundation.org/aboutepilepsy/Diagnosis/seizureprovokingtriggers.cfm

http://www.epilepsy.com/epilepsy/provoke\_seizure

**Epilepsy Organizations** 

http://www.autismspeaks.org/family-services/epilepsy

### CONTACT INFORMATION

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