

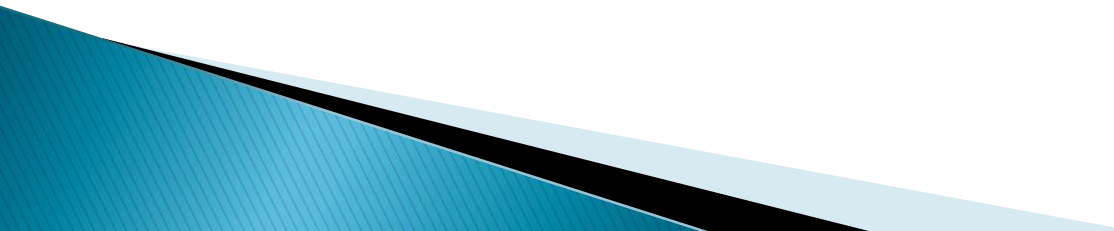
Living with Epilepsy and Seizure Disorders Family Café 2019

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and
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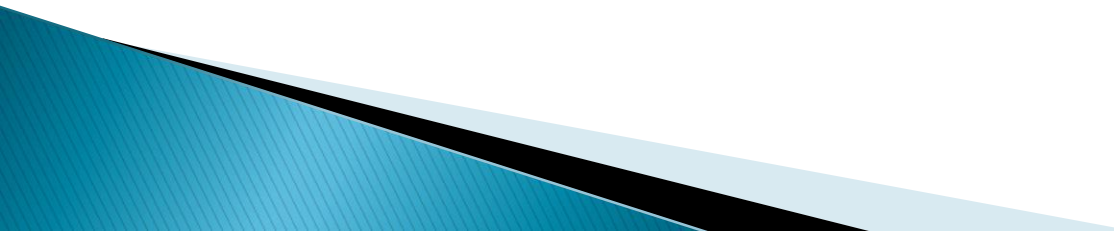
Famous People with Epilepsy

- * 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
 - * Hugo Weaving
 - * Neil Young
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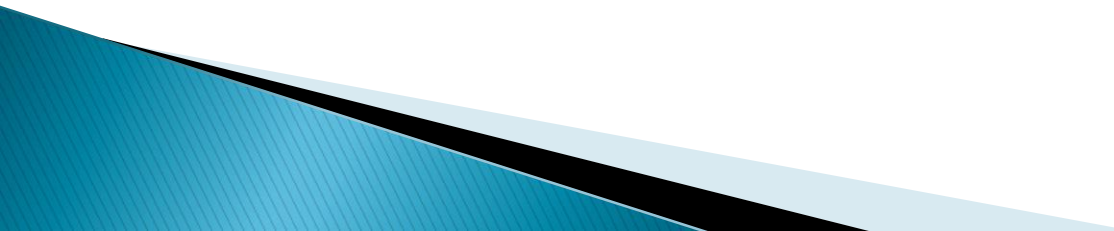
Statistics

- ▶ Epilepsy affects over 3 million Americans of all ages – 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.
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Statistics

- ▶ One in 10 people will experience a seizure in their lifetime.
 - ▶ One in every 100 people will develop epilepsy.
 - ▶ Almost 500 new cases of epilepsy are diagnosed every day in the United States.
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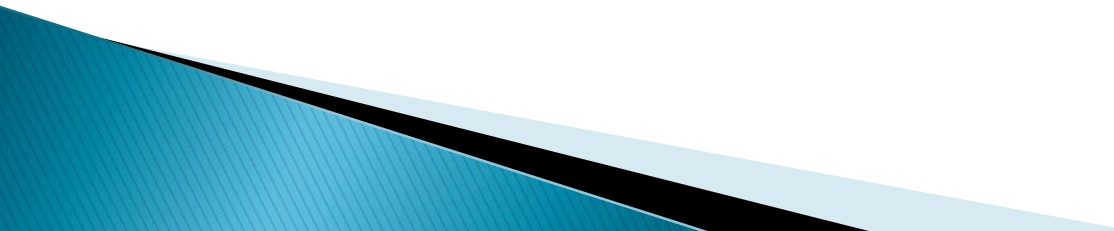
Statistics

- ▶ 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 $\frac{1}{2}$ of 1% of that is spent on epilepsy.
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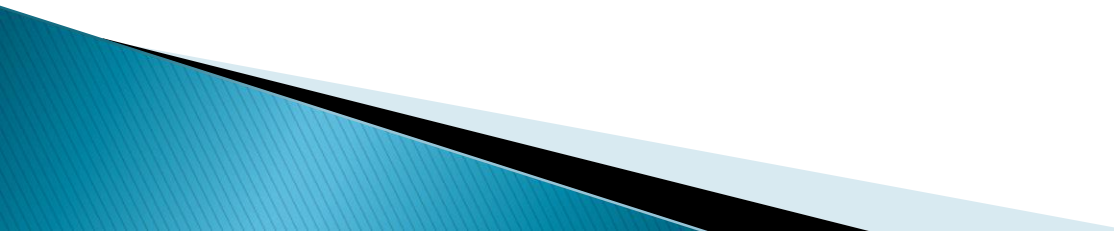
Causes of Epilepsy

- ▶ 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
- ▶ Epilepsy can develop at any age

Types of Seizures

- ▶ There are over 40 different types of seizures.
 - ▶ Seizures are classified into two main types: **generalized** and **partial (focal)**.
 - ▶ **Generalized seizure:** seizure spreads through the entire brain, many brain functions may be involved
 - ▶ **Partial (focal) seizure:** electrical activity is localized or isolated to a specific area of the brain
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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
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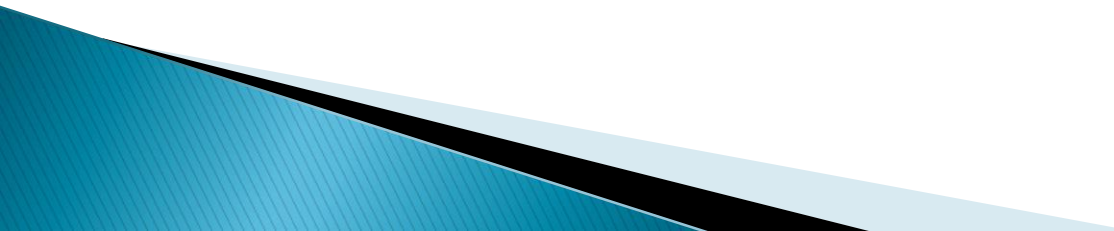
Types of Partial Seizures

There are two types of partial seizures:

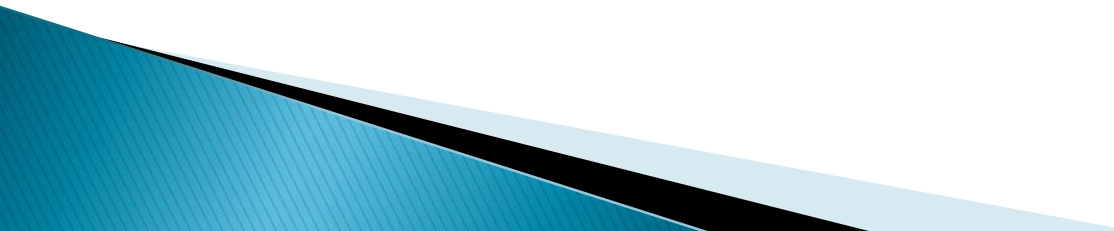
- ▶ **Complex partial seizures**--consciousness is impaired or lost
- ▶ **Simple partial seizures**--consciousness is retained
- ▶ Simple partial seizure types –Motor, Sensory, Autonomic, Psychic

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

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.
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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
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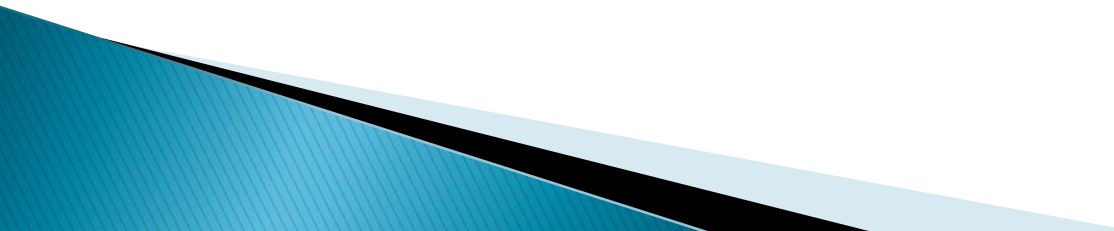
Women and Epilepsy

- ▶ 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.
- ▶ 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.

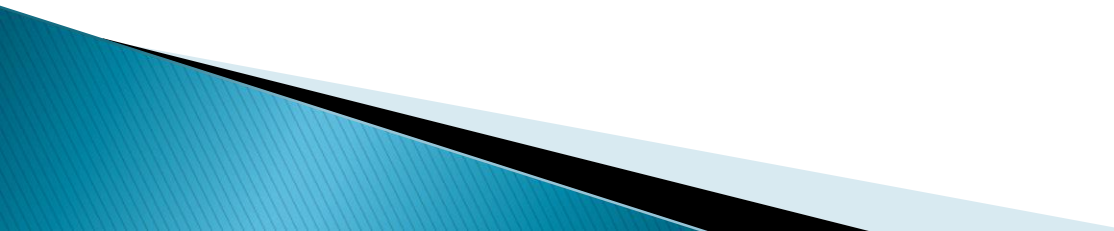
Co-Existing Disorders

- ▶ Developmental Disorders
 - ▶ Metabolic Disorders
 - ▶ Migraine
 - ▶
 - ▶ Pulmonary Disorders
 - ▶ Renal Disorders
 - ▶ Sleep Disorders
 - ▶ Infantile Spasms
 - ▶ Lennox– Gastaut Syndrome
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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.
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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.
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Hydrocephalus and Epilepsy

- ▶ Seizures are not a common occurrence for people with hydrocephalus. (restate)
- ▶ Studies have shown that the most likely reason for the development of epilepsy associated with HS(?) 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.
- ▶ The scientists found that seizures interfere with neurological function that affects social functioning in the brain--causing the similar characteristics to autism.

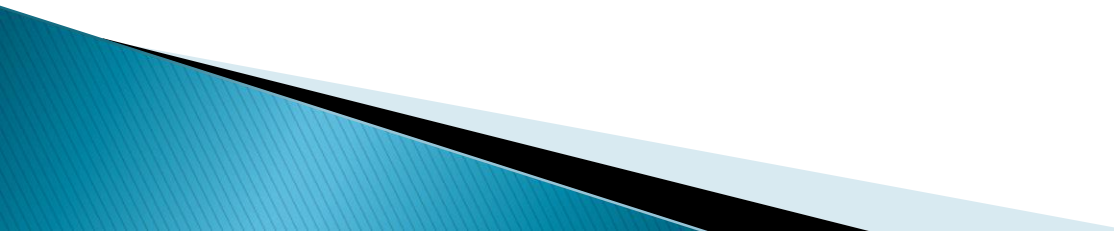
Autism and Epilepsy

- ▶ 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.

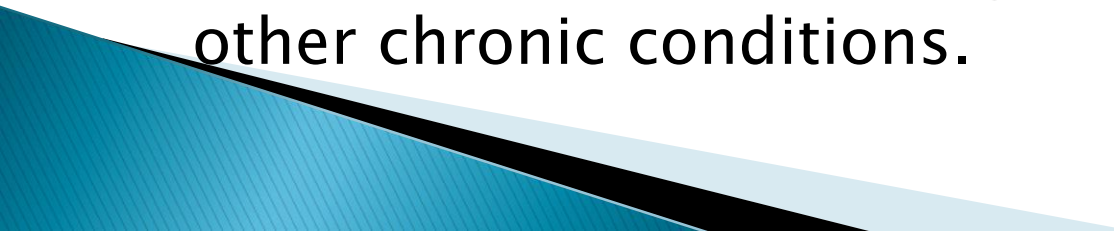
Autism and Epilepsy

- ▶ *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.
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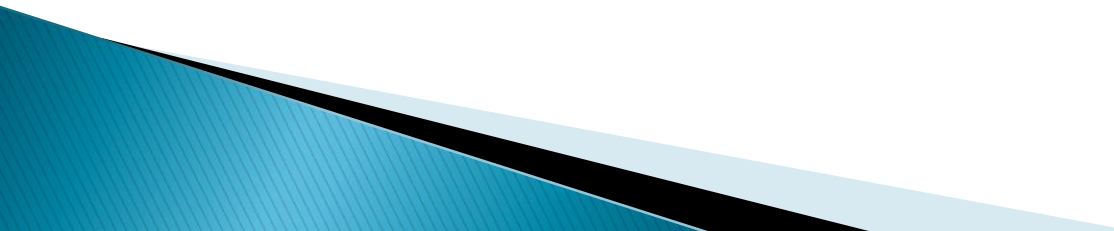
Mood Disorders and Epilepsy

- ▶ 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
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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 with other chronic conditions.
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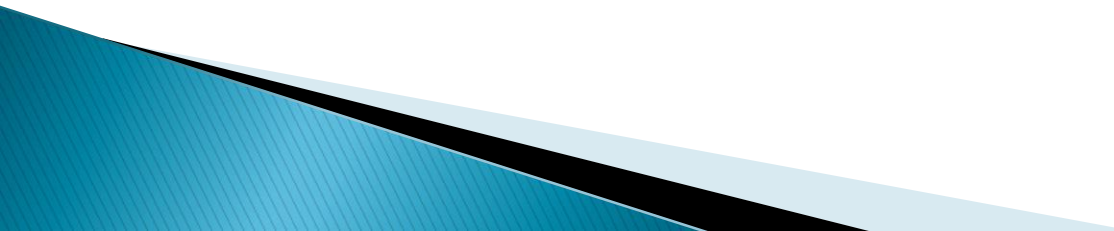
Cognition and Epilepsy

- ▶ 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.
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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

Treatments for Epilepsy

- ▶ Anti-Epileptic Medications
 - ▶ Diet (Keto Diet)
 - ▶ Epilepsy Surgery
 - ▶ Vagus Nerve Stimulation
 - ▶ Deep Brain Stimulation
 - ▶ Medical Marijuana and CBD Oil
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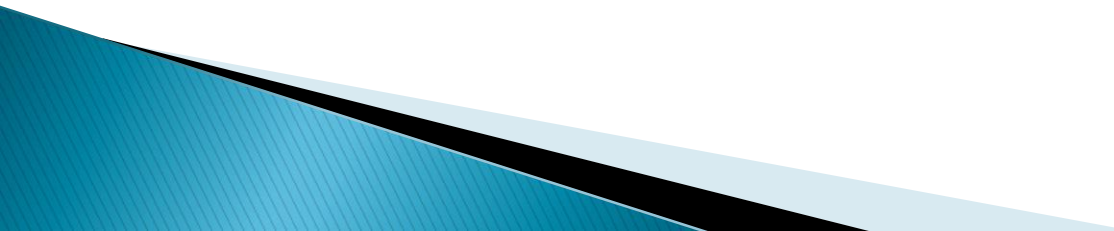
The Epilepsy Pipeline Community Conference

- ▶ A conference sponsored by the Epilepsy Foundation held most years to discuss new treatments, devices, therapies, and much more.
- ▶ The conference in 2016 was held in San Francisco, CA. No Pipeline Conference was held in 2017 and 2019, but Antiepileptic Drug Trials Conferences were held in its place.
- ▶ They post the information from the conferences online.

<https://www.epilepsy.com/make-difference/research-and-new-therapies/engagement/2020-epilepsy-pipeline-conference/2018>

<https://www.epilepsy.com/make-difference/research-and-new-therapies/engagement/conferences/antiepileptic-drug-trials-xv>

Research on New Treatments for Epilepsy

- ▶ Medical Cannabis–Cannabidiol
 - ▶ New medications for drug-resistant epilepsy.
 - ▶ Surgery separating the posterior quadrant of the brain
 - ▶ Transcranial Magnetic Stimulation (TMS)
 - ▶ EEG Patch to track seizure
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Genetic Testing for Epilepsy

- ▶ Helpful for anyone with a suspected genetic cause of epilepsy.
- ▶ Can help confirm a specific diagnosis.
- ▶ May also give information about associated neurological or medical conditions that may arise over time.
- ▶ May assist in selecting an appropriate seizure medication or special diet.
- ▶ May help to limit invasive or unnecessary testing.
- ▶ May assist with understanding the prognosis or outlook of a person's epilepsy and provide a basis for further genetic counseling for families.


Devices For Epilepsy

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


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.

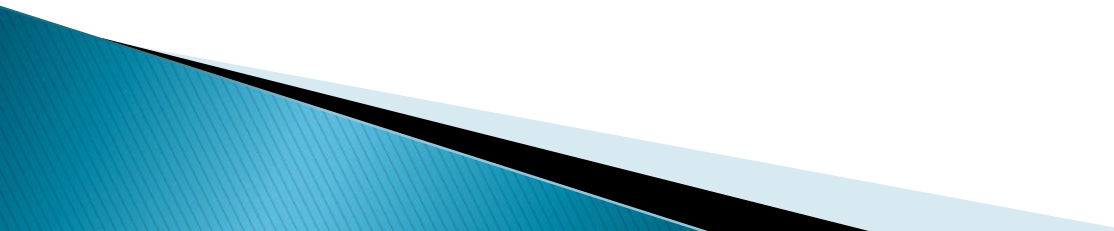
Examples of Accommodations and Services for Students with Epilepsy

- ▶ Individualized Healthcare Plan: detailed plan for school staff and school nurse to assist student during seizures and handle other medical affects of epilepsy at school.
 - ▶ Supervision to assist with moving around school safely and to help redirect and review material missed during absence seizures.
 - ▶ 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.
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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.
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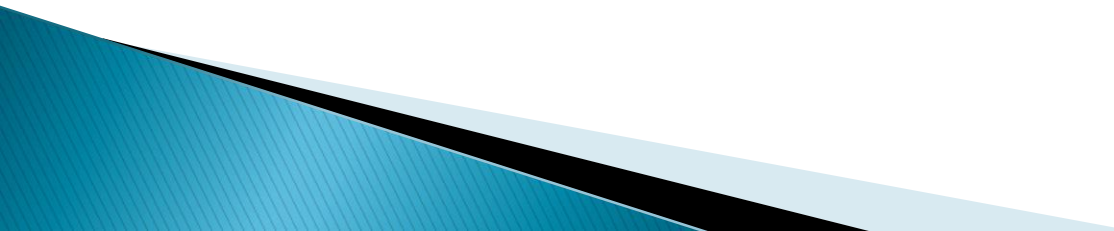
Discrimination

- ▶ **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.
 - ▶ These laws cover discrimination in the school, in the workplace, in government services, in housing, and in public accommodations (public businesses).
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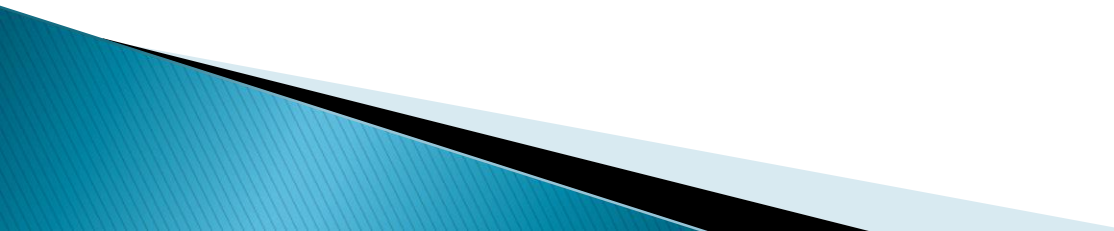
Epilepsy in the Workplace

- ▶ Workers with epilepsy are entitled by law to request **accommodations** that will enable them to perform their job.
 - They must be otherwise qualified for the job.
 - The requested accommodation must be reasonable.
 - The accommodation must not cause undue burden on the employer.
- ▶ <https://www.eeoc.gov/laws/types/epilepsy.cfm>

Epilepsy in the Workplace

- ▶ **Interview questions** must be related in some way to the ability of the candidate to perform the job.
 - ▶ Applicants/Employees do not have to **disclose** their diagnosis unless they are using it as the basis for requesting 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.
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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.
- 

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.




Risks of Mixing Seizure Drugs with Other Medications or Recreational Drugs

- ▶ In addition to taking the risk of not having your seizure medication work effectively, mixing seizure meds with other drugs can be lethal and can cause an overdose of your medication.

So You Think You or Someone You Know Is Having Seizures, but they 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
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Epilepsy Organizations

- ▶ Epilepsy Foundation
 - ▶ Epilepsy Foundation: Florida
 - ▶ Epilepsy Association of Central Florida
 - ▶ Epilepsy Florida www.epilepsyfl.com
 - ▶ CURE: Citizens United for Research in Epilepsy
 - ▶ FACES: Finding a Cure for Epilepsy and Seizures
 - ▶ Epilepsy Society–UK
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Resource Websites

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

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- › New Treatments for Epilepsy
 - › <http://www.medicalnewstoday.com/articles/277338.php>
 - › <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 Organization
 - › <http://www.livingwithepilepsy.org/family-services/epilepsy>

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