

# Advocating for Your Child with Epilepsy

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**EPILEPSY**  
FOUNDATION®

MICHIGAN

# Advocating for Your Child with Epilepsy

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# Mission of the Epilepsy Foundation

To lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.



# Purpose

To provide a better understanding of epilepsy and how to effectively support students with seizures by:

- Creating a safe and supportive school environment
- Supporting positive outcomes
- Advocating for a student with seizures
- Understanding Mental Health and Emotion Issues



An ideal setting...

**This video also on YouTube:** <https://youtu.be/XyDHG02phs0>



# The Brain, Seizures and Epilepsy



# The Brain & Seizures

- A seizure occurs when there is a temporary change or disruption in the way the brain sends electrical signals
- During a seizure, there is a “short circuit” in the way messages are sent between brain cells
- **Not everyone who has a seizure has epilepsy**
- Seizures can occur with other conditions (e.g. blood sugar problems, head injury, fever)

Fisher RS et al. (2017) Epilepsia, 58(4),522.

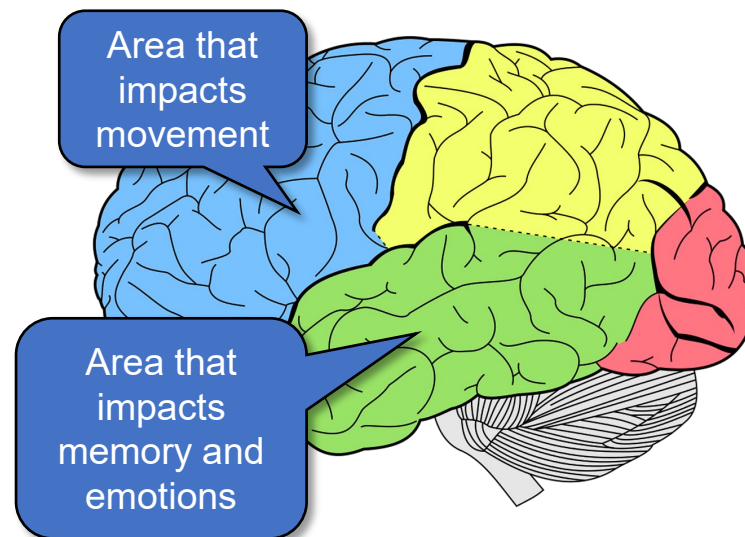


# What Do Seizures Look Like?

What a seizure looks like depends on the area of brain involved.

## Seizures can result in a change in

- Movement
- Sensation
- Behavior
- Speech
- Awareness



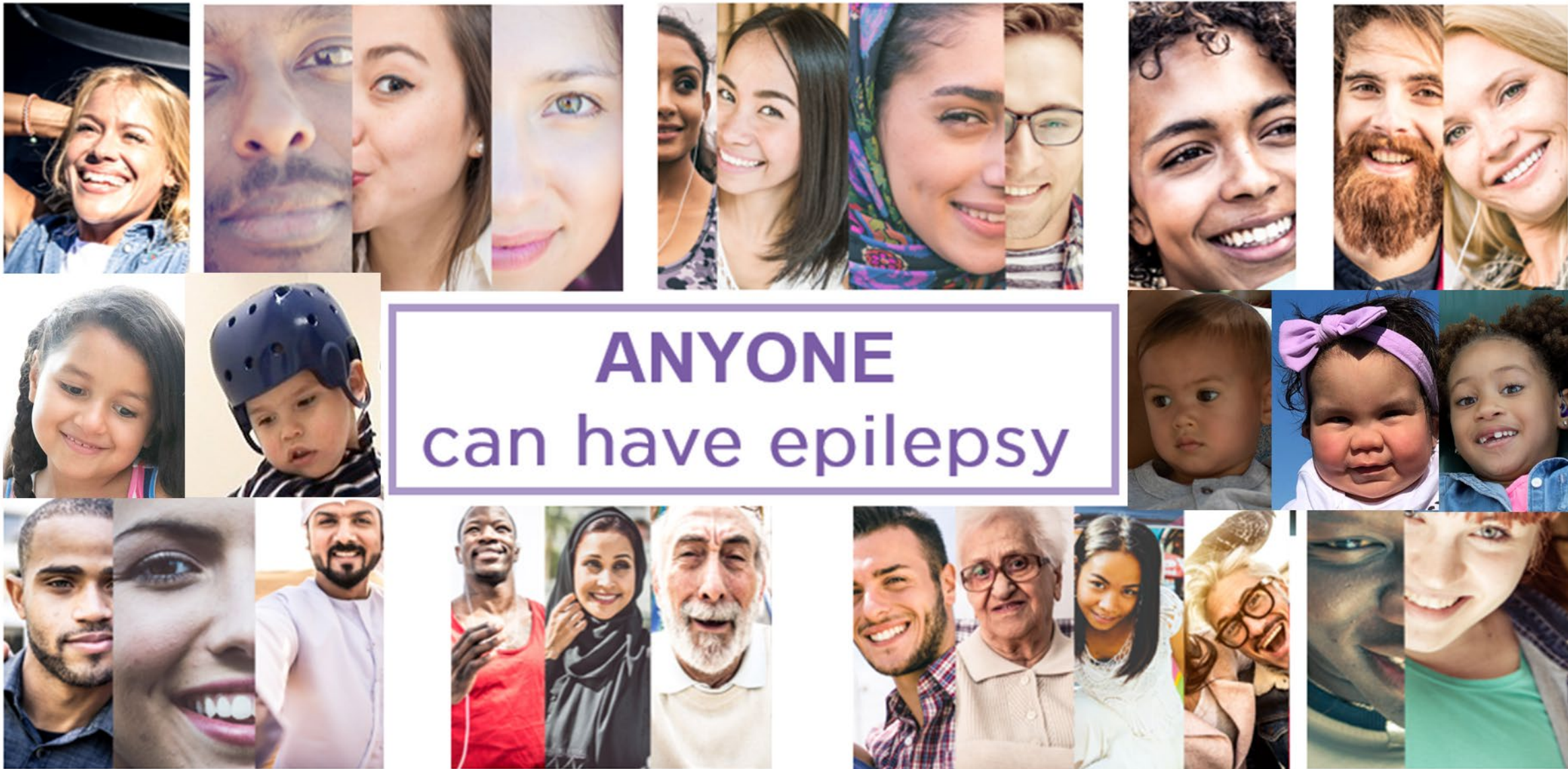
Seizure symptoms and signs of seizures vary from person to person... **but** they are usually consistent and predictable for each individual

# What is Epilepsy

- Epilepsy is a chronic brain disease characterized by **recurrent unprovoked seizures.**
- Sometimes referred to as a “seizure disorder”
- Many different types of epilepsy
- Diagnosis does not indicate cause or outlook

Fisher RS et al. (2014) Epilepsia, 55(4), 475.

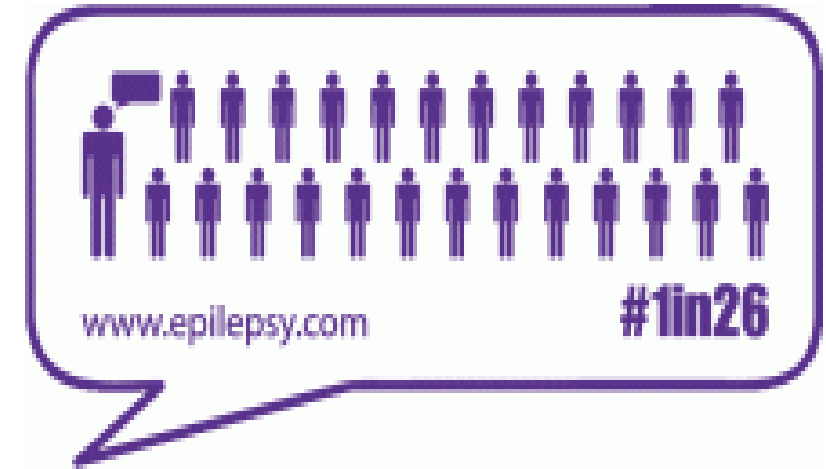
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**ANYONE**  
can have epilepsy

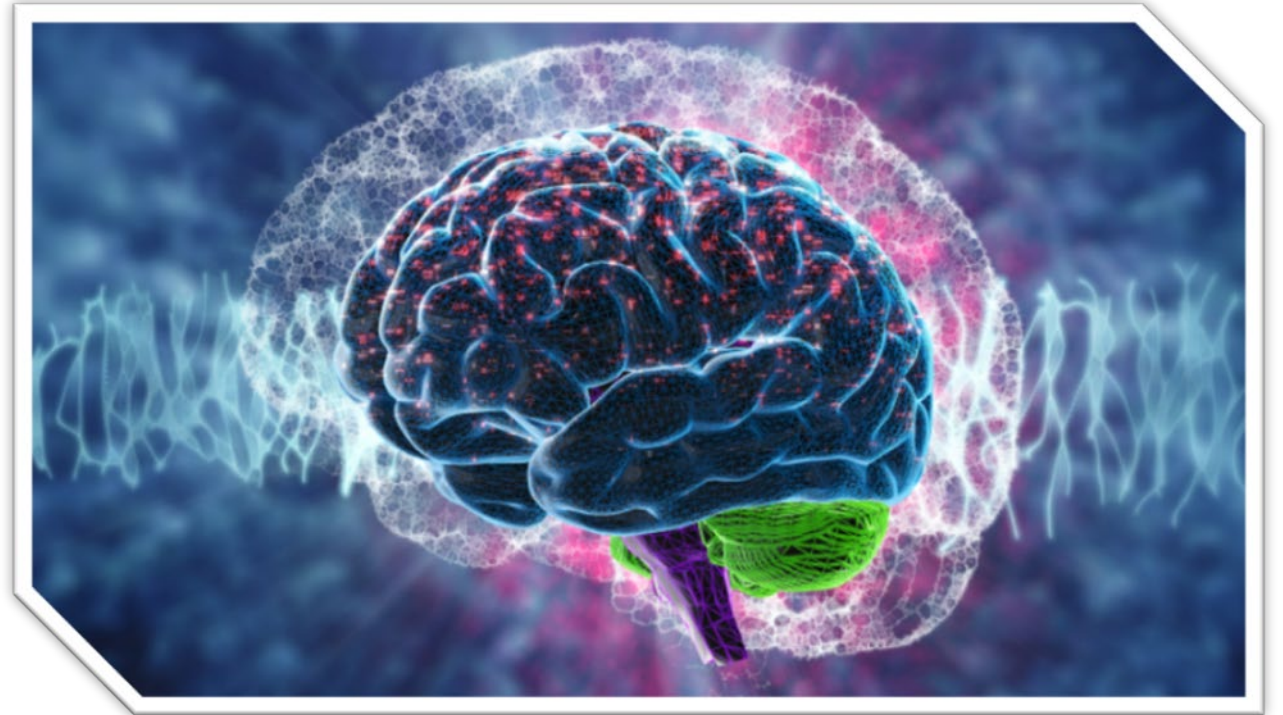
# Epilepsy By The Numbers

- 3.4 million in the U.S. with active epilepsy
  - ❖ 470,000 youth 17 years or younger
  - ❖ 1 in 3 people have uncontrolled epilepsy
  - ❖ Nearly 14,000 children in Michigan have epilepsy
- 1 in 26 people will be diagnosed with epilepsy during their lifetime
- 1 in 10 people worldwide will have a seizure during their lifetime



# Risks & Fears Related to Seizures

- Physical injury
- Difficulty breathing
- Drowning
- Prolonged Seizure Activity
- Seizure emergencies
- Early death
  - Accidents or drowning
  - Breathing or heart problems
- Sudden Unexpected Death in Epilepsy (SUDEP)
  
- Suicide



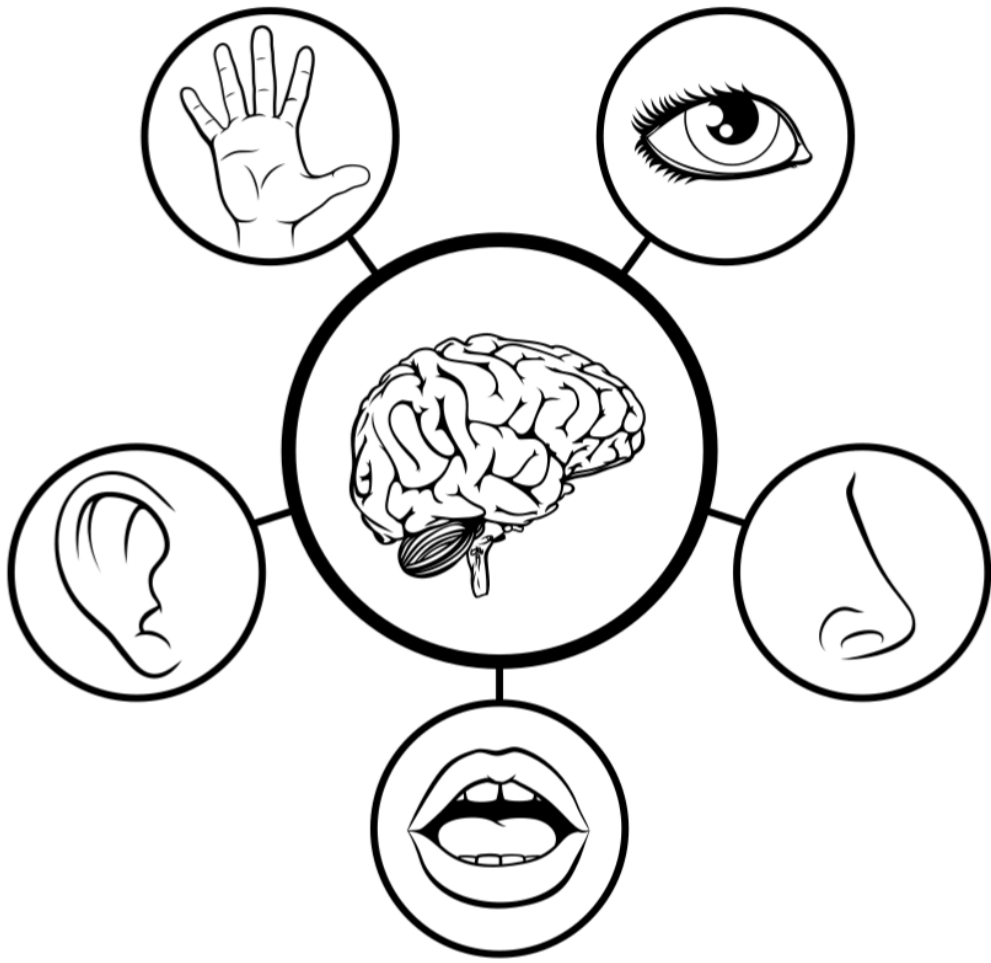
# Prevalence of Learning Problems

- 50% of children with epilepsy (CWE) have school-related difficulties
- 25% of CWE have a learning disability
- Risk of learning problems 3x higher than general population
- Epilepsy Foundation of MI Needs Assessment:
  - 64% of CWE experienced school performance problems related to epilepsy

# The Spectrum of Impact

- Can range from frequent seizures and intellectual disability to full seizure control and no cognitive impact
- Most CWE fall within the normal range of IQ, but more have scores in the low-normal range than in the general population
- Cognitive difficulties may be subtle or transient and therefore not easily recognized
- Even “benign” forms of epilepsy (benign rolandic, childhood absence) are associated with learning problems – including after child has outgrown seizures





# Types of Seizures

# Seizure Types

And How they are Classified

## Focal Onset Seizures

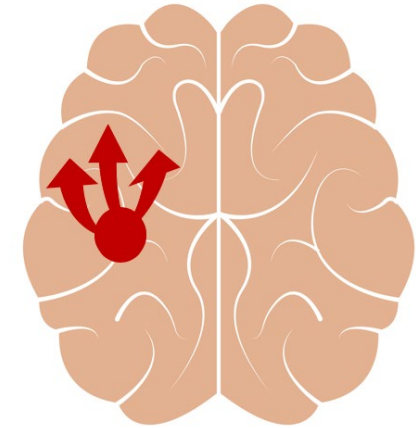
- Involve only part of the brain
- Common types – focal aware and focal impaired awareness

## Generalized Onset Seizures

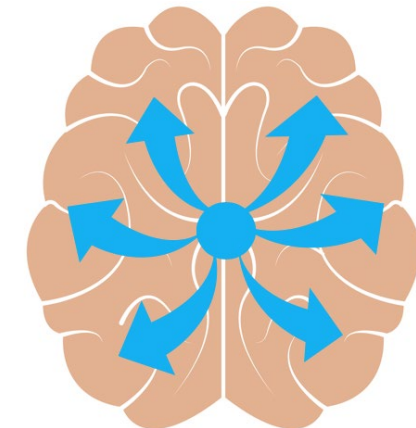
- Involve both sides of the brain
- Common types – absence and tonic-clonic

## Unknown

- Where it starts is unknown



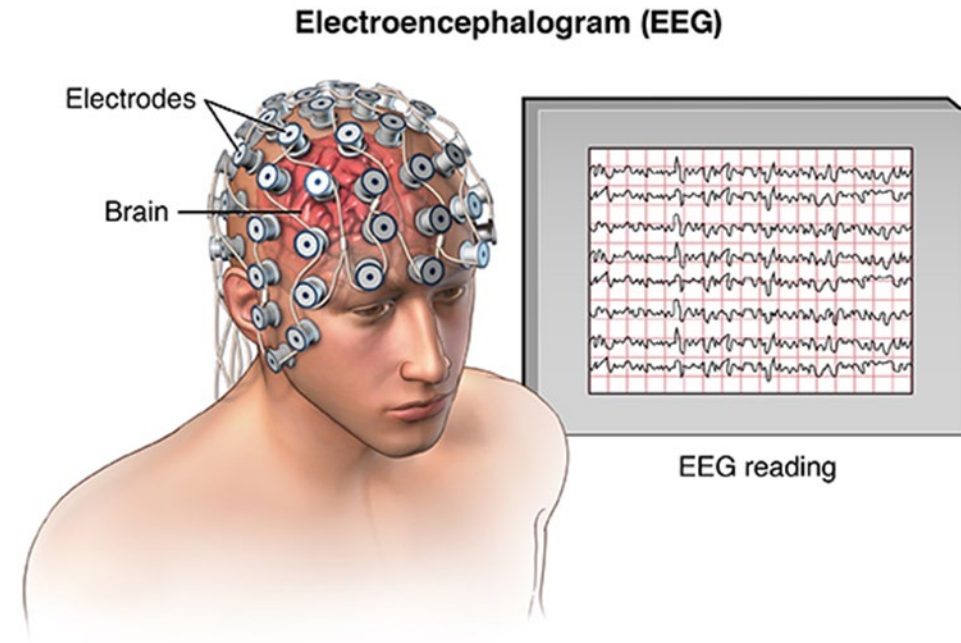
**FOCAL**



**GENERALIZED**

# Functional Seizures or Psychogenic Nonepileptic Seizures (PNES)

- Behavioral events that resemble seizures
- Epileptic seizures are caused by sudden abnormal electrical discharges in the brain
- Epileptic seizures have characteristic EEG changes during the seizure
- EEG testing shows no electrical disturbance associated with typical events during a psychogenic nonepileptic event
- PNES are caused by stressful psychological experiences or emotional trauma





# School Education and Impact Triggers & Contributing Factors in Learning



While every student goes through transitions as they age and enter adolescence over the course of their education, there are a number of significant changes that take place for students living with epilepsy. This can include changes in seizure patterns, treatment strategies, social and emotional effects, medication side effects, depression, mental health concerns and responsibilities for self-management.

# Seizure Triggers

## Missed Medicines

Missing doses of seizure medicine is the most common cause of breakthrough seizures.

## Lack of Sleep

If you have epilepsy, lack of "good sleep" may make it more likely for you to have a seizure.

## Stress

Stress is an expected and unavoidable part of life. This includes excitement, both positive and negative.

## Alcohol & Recreational Drugs

Alcohol may interfere with certain anti-seizure medications. The effects and risks of recreational drugs vary greatly.

## Hormones

The brain contains many nerve cells that are directly affected by estrogen and progesterone, the main sex hormones in women.

## Sensitivity to Light

About 3% of PWE: exposure to flashing lights at certain intensities or to certain visual patterns can trigger seizures.

## Other Illnesses

Head colds, lung infections or sinus infections (caused by viruses or bacteria) can often lead to a change in seizures.

## Nutritional Deficiencies

Low levels of sugar, mineral's sodium, calcium and magnesium can alter the electrical activity of brain cells and cause seizures.

## Over the Counter Medication

This is especially true for medicines to treat colds, allergies, and sleep problems.

# Contributing Factors for Learning

- Underlying brain injury/condition
- Medication side effects
- Effects before, during, & after seizures
- Brain injury from status epilepticus
- Absenteeism
- Poor Sleep

# Contributing Factors: Brain Injury / Condition

- Underlying condition, such as CP, autism, intellectual disability, TBI, etc., may be primary cause of learning difficulties

However...

- Important not to automatically attribute all learning problems to primary disability; some may be related to epilepsy and potentially reversible



# Contributing Factors: Medication Side Effects

- Tendency to over-attribute cognitive problems to antiseizure medication side effects
- Polytherapy, rapid initiation, and high doses increase chances of cognitive/behavioral side effects
- Every antiseizure med has potential to cause cognitive, behavioral, or psychological side effects

# Contributing Factors: Medication Side Effects (Continued)

## Common Side Effects:

- Impaired attention
- Drowsiness
- Slowed processing speed
- Coordination problems
- Hyperactivity
- Mood changes (e.g. depression, irritability)

# Contributing Factors: Effects Before, During & After Seizures

## **Before** (*preictal*)

- Premonitory Symptoms (headaches, anxiety, irritability) may be distracting & cause worry about imminent seizure

## **During** (*ictal*)

- Impairment of consciousness leads to missed information (especially with unrecognized absence seizures)
- Simple partial seizures (auras) can be distracting and may not be reported

## **After** (*postictal*)

- Confusion and sleepiness (most common)
- Psychosis, depression, muscle soreness, headache, weakness, paralysis, blindness, loss of sensation, loss of speech
- Duration of symptoms varies (from a few minutes to several days)
- Teacher may assume student is back to normal, but subtle postictal symptoms may persist

# Contributing Factors: Absenteeism

- Often due to frequent medical appointments and/or seizures
- Make sure school is not sending child home unnecessarily; sometimes child can return to class after seizure (after a brief rest)

# Contributing Factors: Poor Sleep

- Several epilepsy syndromes involve nocturnal seizures
- Any seizure at night can reduce sleep quality and affect cognition
- Some antiseizure medications can interfere with sleep
- Sleep disorders more common in PWE
- Sleep deprivation is common seizure trigger (in addition to affecting cognition)



## Strategies for Improving School Performance

# Seizure Action Plans

Should be available for each student with epilepsy & it should be included in the students IEP.

Provides information about:

- Seizure first aid
- Specific instructions for each student
- When a seizure may be an emergency
- When to give rescue therapy
- Who to call

- Helps organize information to care for those known to have seizures
- Made under the guidance of a healthcare team
- Helps you know what to do to prevent an emergency

**SEIZURE ACTION PLAN (SAP)** 

Name: \_\_\_\_\_ Birth Date: \_\_\_\_\_  
Address: \_\_\_\_\_ Phone: \_\_\_\_\_  
Parent/Guardian: \_\_\_\_\_ Phone: \_\_\_\_\_  
Emergency Contact/Relationship: \_\_\_\_\_ Phone: \_\_\_\_\_

Seizure Information

Seizure Type	How Long It Lasts	How Often	What Happens

Protocol for seizure during school (check all that apply)

First aid – **Stay. Safe. Side.**  Contact school nurse at \_\_\_\_\_  
 Give rescue therapy according to SAP  Call 911 for transport to \_\_\_\_\_  
 Notify parent/emergency contact  Other \_\_\_\_\_

**+** First aid for any seizure

STAY calm, keep calm, begin timing seizure  
 Keep me **SAFE** – remove harmful objects, don't restrain, protect head  
 **SIDE** – turn on side if not awake, keep airway clear, don't put objects in mouth  
 STAY until recovered from seizure  
 Swipe magnet for VNS  
 Write down what happens \_\_\_\_\_  
 Other \_\_\_\_\_

**When to call 911**

Seizure (loss of consciousness) longer than 5 minutes  
 Repeated seizures without recovery between them  
 Rescue medicine/therapy doesn't work  
 Injury occurs or suspected, seizure in water  
 Difficulty breathing after seizure  
 Person does not return to usual behavior after seizure  
 First time seizure  
 Other medical problems or pregnancy need to be checked

**+** When **rescue therapy** may be needed:

**WHEN AND WHAT TO DO**

If seizure (cluster, # or length) \_\_\_\_\_  
Name of Med/Rx \_\_\_\_\_ How much to give (dose) \_\_\_\_\_  
How to give \_\_\_\_\_

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If seizure (cluster, # or length) \_\_\_\_\_  
Name of Med/Rx \_\_\_\_\_ How much to give (dose) \_\_\_\_\_  
How to give \_\_\_\_\_

# Advocating and Tailoring Care for Your Student

## Consider the following

- Seizure - type, how long it lasted, and what happened
- Recovery period – how long it lasted, what happened, safety
- Setting – classroom, stairs, parking lot
- Potential for injury
- Resources
  - Staff training in seizures recognition and first aid, and rescue medicines
  - School Nurse, MERT Team, Coaches, Aides, Office Staff
  - Seizure action plan
  - School policy



# Common Pitfalls

**Educators may assume school performance problems are due to lack of motivation**

- Normal IQ
- Intermittent nature of epilepsy (school performance may wax and wane)












**Transient impairment during assessment may lead to under- or overestimation of abilities**

- Make sure epilepsy-related variables are noted and taken into account when interpreting results

# Strategies for Improving School Performance: Evaluation & Accommodations

- Request a medical management meeting and **504 plan creation** (epilepsy is a disability under the ADA – Civil right)
- Request evaluation for SE services and **creation of IEP** (categories OHI, can be specific Learning Disability, TBI, emotional disturbance, intellectual disability, multiple disabilities)
- Test results show disability does not significantly impact learning, build up the accommodations on the 504 and request **independent neuro-psych evaluation**

# 504

Section 504 of the Rehabilitation Act of 1973	 Governing Law	Individuals with Disabilities Education Act amended 2004
U.S. Department of Education: Office of Civil Rights	 Overseeing Agency	U.S. Department of Education: Office of Special Education and Rehabilitation Services
Student must have a disability AND the disability affects the student's ability to access the curriculum.	 Eligibility	Student must qualify in one of 13 categories of disability, AND disability affects the child's ability to access curriculum.
Does not require written plan.	 Written Plan	Does require a written plan.
Law does not specify evaluation procedures. Simply states "periodic" evaluation.	 Evaluation	Initial evaluation using standard assessment tools. Student must be reevaluated every three years.
School must get permission to evaluate. School can create a plan without parent participation.	 Parent Involvement	Parents are required to be part of the IEP team.
Curriculum is not customized for the student. The student completes the same curriculum as students without disabilities.	 Customized Curriculum	The IEP must be an individualized plan that meets the needs of the student.
No requirement to review annually.	 Annual Review	Must review the plan annually. Student must be reassessed and requalified every 3 years.
No goals or progress monitoring.	 Goals	Goals must be written, measurable and reviewed annually.
Student may be given accommodations to "equal the playing field" so they are able to access curriculum.	 Accommodations	Students may be given accommodations to make it easier to access their education.
The student can have modified assignments. The student cannot have a completely different curriculum.	 Modifications	The student can have modified assignments or modified curriculum.
The student is not eligible to receive extra services.	 Services	The student is eligible to receive services such as speech therapy, occupational therapy, etc.

# IEP

It's important to remember that every student's abilities and needs will be different and can change for a number of reasons over the course of their education.

# Conversation for Improving School Performance: **Services & Accommodations**

- Full-time or part-time aid
- Access to a resource room
- Speech/language therapy
- Occupational therapy
- Training to address specific learning disabilities
- Tutors
- Psychological counseling
- Efforts to raise awareness & reduce stigma
- Medical accommodations, designation and recovery

# Conversation for Improving School Performance: **Services & Accommodations (Continued)**

- Testing accommodations (e.g. notes, extra time)
- Written notes or recording of spoken lessons
- Assistive technology (including smart phones)
- Minimizing visual or auditory distractions
- Repetition of information after seizures
- Changing schedule so that less challenging classes take place during periods of lower functioning

# Questions for School Administration

Access to axillary services –

- Have a school nurse or district nurse? Hours worked, responsibilities, contact number, do they handle staff education on epilepsy and how much time is given (suggest EFA online course)
- Nurse who is designated to handle medical issues? Who designates?
- Policies on medication administration (teachers, axillary staff, bus drivers), forms needed, permissions, scripts, med forms.
- 4 hour medication administration classes (state suggested) does your staff take them
- Access to monitored post-seizure recovery area? Is this a monitored area?

# Questions for School Administration

## (Continued)

- Attendance Policies? Methods to accommodate child's absences without penalty
- Home bound or hospitalized students accommodations and school staff responsibility in keeping child up with program, how to request? (plan ahead in cases of VEEG, Surgery)
- Suspension policies, acceptations for mental health issues?
- Bullying prevention methods, investigation methods, counseling for perpetrators and victims

# In Conclusion

**Students with Epilepsy often need accommodations and special considerations, even if seizures are subtle or transient. Understanding a diagnosis and available supports will help guide conversation.**

**Multiple factors contribute to seizures, learning difficulties and individualized needs. Communication is key. Families and staff are a key contributor to a student's success.**

**School support is modifiable. School training is available to staff (including support staff) and it is appropriate for you to request that staff understand a student's needs on all levels.**

**Other Support: Michigan Alliance for Families and the Epilepsy Foundation of Michigan can help in guiding conversation and advocating for students with epilepsy.**





## Supports and Services Available

# Supports & Services

- Monitoring for changes in behavior and mood, with early intervention requesting a 504, with testing for IEP, possible neuropsychiatric independent evaluation
- Social work and school psychologist consult. Possible creation of behavioral intervention plan
- Disability Manifestation Determination review to prevent unfair discipline or suspension
- 1:1 ParaPro request, change in placement or home schooling accommodations with severe
- Constant contact with teachers and school staff with changes in student's meds and seizure activity/daily behavior log

# Supports & Services (Continued)

- **Mental Health** – develop a working collaborative relationship (someone student can talk with), convey a caring attitude, avoid negative techniques such as punishment, sarcasm, avoid criticism and create a positive learning environment. Give extra time on assignments and tests, break down assignments into smaller sections, pair up with a student willing to help. Assist with organization, setting up schedules, study habits.
- **Emotional support** includes encouraging student to use anxiety-reducing techniques, allow self-calming objects, breaks, encourage open door with social worker when feeling anxious. Consider classroom setup and routines. Assign student a designated “buddy” for out of class opportunities. Allow preferential grouping for field trips. Allow break pass (with buddy) as needed, create a plan for catching up after absence or illness to decrease anxiety.

# Supports & Services (Continued)

- **Memory** – develop a working collaborative relationship (buddy system, small workgroups, 1:1 aide or ParaPro), convey a caring attitude, avoid negative techniques such as punishment, sarcasm, avoid criticism and create a positive learning environment. Give extra time on assignments and tests, break down assignments into smaller sections, pair up with a student willing to help. Assist with organization, setting up schedules, study habits. Accommodations to build self-esteem, socialization skills.
- Understand and incorporate accommodations for educational performance affected by memory, organization, slower processing skills, etc. that can occur (pre-, inter-, and post-ictal seizure effects)

# Supports & Services (Continued)

- Give advance notice of planned substitute, changes in routine, and time before upcoming transitions.
- Ensure all substitute staff are aware of students IEP, 504, Seizure Action Plan
- Give instructions clearly, write down expectations.
- Provide the student with a signal if unable to clearly communicate needs without interruption to classmates.
- Let students share their story, if desired.
- Limit attention activities or provide individual opportunities for presentations, reading aloud, etc.
- Provide extended time on tests, different location, supports as needed.
- Encourage brain breaks, talk through behavior problems and monitor student's emotional state or frustration one-on-one.

# Treatment

Goal of treatment is early intervention to improve coping, prevent/reduce future difficulties, such as loss of friendships, failure to reach social and academic potential, and feelings of low self-esteem.

- Evaluation from a qualified mental health professional (e.g., psychologist, psychiatrist)
- Medications – SSRI and SNRI's specifically reported to not decrease seizure threshold
- School Support
- IEP/504, BMP, to include goals, interventions to address concerns in the school setting. \* Also ask for Manifestation Determination review to avoid unfair discipline or punishment

# Additional Support Services

- Therapy/Counseling
- Cognitive Behavioral Therapy (CBT)
- Camp (for students with epilepsy)
- Psychoeducational and Support Groups
- Case Management, CMH, CSHCS
- Behavioral Health Therapy
- Play Therapy / Art Therapy
- Educational Supports (IDEA, 504), School social work, Behavioral Management, OT, ST, PT
- Health Agencies (Michigan Alliance for Families, EFM, 211, etc.)

**E·SMART**



Epilepsy Self-Management, Advocacy, & Resilience for Teens



**The Arc**  
Michigan

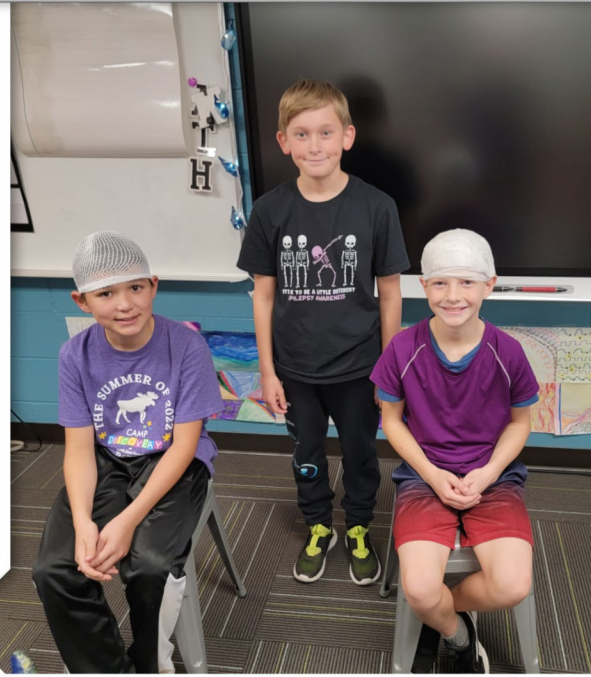






# Inclusion Opportunities

- Talk with student
- No mimicking or posting of person during a seizure
- Intervene consistently
- Educate students, classrooms and school groups (assemblies, fundraisers, etc.)
- Encourage *peer support*
- Support Abilities Campaign
- Support Special Observance Days (Purple Day for Epilepsy)
- **Be involved**



# Epilepsy Foundation School Resources

- *Seizure Training for School Personnel*
- Take Charge Epilepsy Education Series
- Videos on Seizure First Aid, Rescue Therapies, and Seizure Action Plans
- Brochures, videos, pamphlets, fact sheets, posters
- Available at:
  - epilepsy.com
  - epilepsymichigan.org
  - Youtube (<https://www.youtube.com/c/EpilepsyFoundationNational/videos>)

## Information on...

- how/when to seek epilepsy specialty care
- diagnosis & prognosis
- treatment options
- possible comorbidities
- self-management
- psychosocial & cognitive impact
- impact on school & employment
- available resources

## Services include:

- Toll-free Here for You Helpline
- Annual Conferences
- Monthly Learn & Share Conference Calls
- Parent & Young Adult Support Groups
- Individual Advocacy
- Public Policy Advocacy
- Camp Discovery
- Public/Professional Awareness Training
- E-SMART program for teens



# Questions?

Case Study if time allows.

# Thank You for all you do!

GET INFORMATION:

[epilepsy.com](http://epilepsy.com)



[epilepsymichigan.org](http://epilepsymichigan.org)

24/7 Helpline:

1-800-332-1000

Here for You Helpline (MI)

1-800-377-6226



# We are here to support you!

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For more information visit:

<https://www.michiganallianceforfamilies.org>

Call: 800-552-4821

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# Michigan Alliance for Families

Michigan Alliance for Families is an IDEA Grant Funded Initiative of the Michigan Department of Education, Office of Special Education, and Michigan's federal Parent-Training and Information Center (PTIC) funded by U.S. Department of Education, Office of Special Education Programs (OSEP).

[www.michiganallianceforfamilies.org](http://www.michiganallianceforfamilies.org)

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