Beyond the Seizure

Understanding Epilepsy and Supporting Others

Presented by: Natalie L. Boehm, MBA, PC
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About the Presenter

Natalie L. Boehm, MBA, PC, is a strategic consultant, author, disability advocate, and the founder of The Defeating Epilepsy Foundation®. She established the foundation to create better opportunities for individuals living with epilepsy and help improve their quality of life. Natalie was diagnosed at the age of two with epilepsy due to a traumatic brain injury. Through education, advocacy, and community support, she works to reduce stigma and empower people with epilepsy to live with dignity, purpose, and hope.



What we will learn



What is epilepsy, and what are seizures?



Learn first aid and emergency signs.



Explore treatment and action plans.



Build a more supportive community.

What is epilepsy? What are seizures?



Epilepsy is a neurological disorder that causes recurring seizures.



Epilepsy can affect anyone at any stage of their life.



1 in 26 people will be diagnosed with epilepsy in their lifetime. Epilepsy is diagnosed when someone has two or more unprovoked seizures.



1 in 10 people will have a seizure in their lifetime. Just because someone has a seizure does not automatically mean they have epilepsy.



Epilepsy across the lifespan

Around 65 million people worldwide have epilepsy.

- Epilepsy affects people of all genders, ages, and ethnic backgrounds.
- Some people with epilepsy will need treatment their entire lives, while some children may outgrow the condition with age (absence seizures).
- Epilepsy is not contagious.
- There are multiple types of epilepsy and seizures. Personal care is unique and not based on average care.

Causes of Epilepsy



Causes can include injury, stroke, infection, or genetic conditions (mutations).



Structural (brain development), hormonal, and immune causes are also possible.

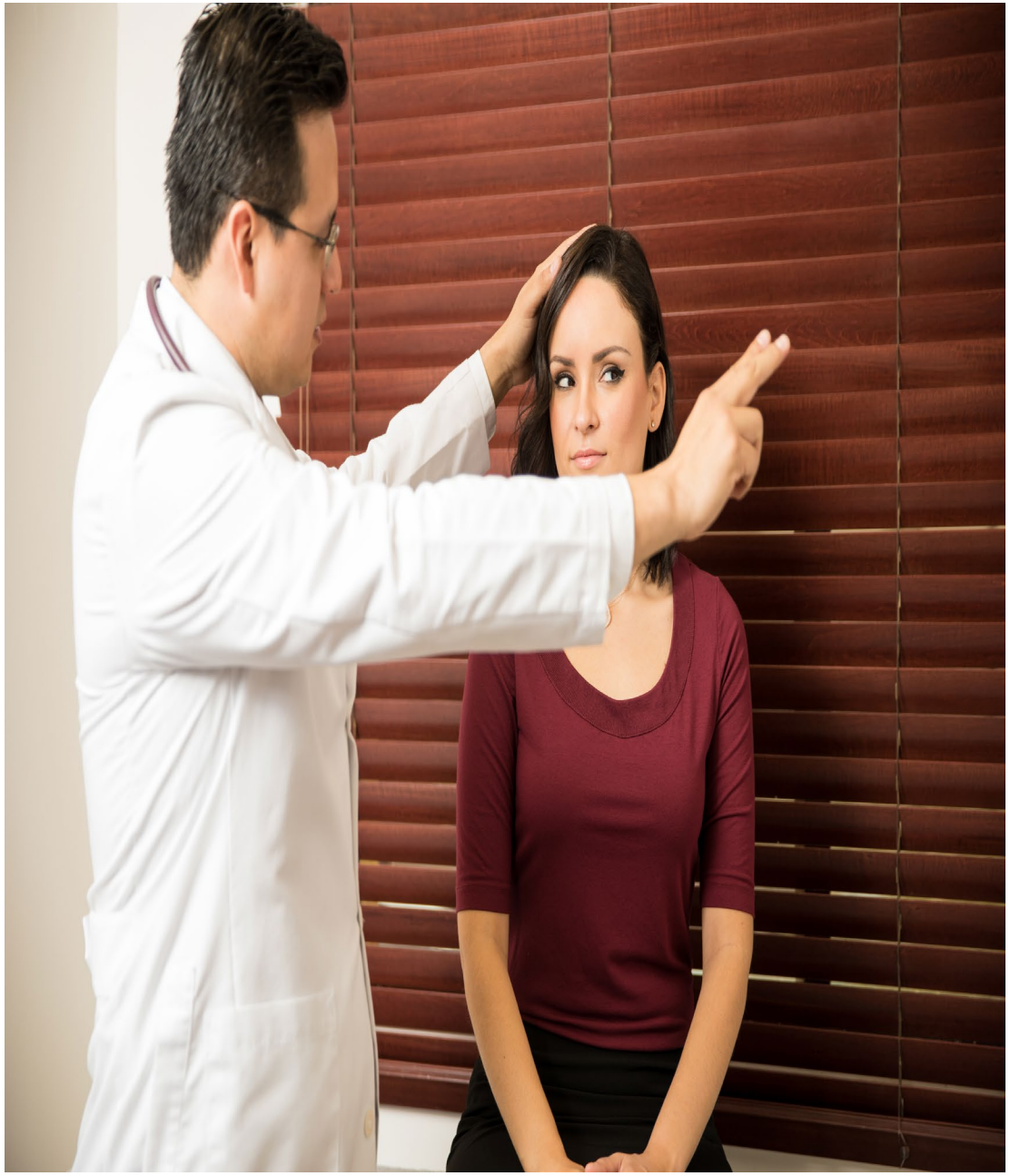


Sometimes the cause remains unknown.

Seizures do not all look alike

There are multiple types of seizures, depending on what area of the brain they are coming from. Symptoms of a seizure include:

- Short-term confusion
- A staring spell
- Stiff muscles
- Jerking movements of the arms and legs
- Loss of consciousness
- Psychological symptoms such as fear, anxiety, or déjà vu.



A simple seizure classification map



Focal: networks within one hemisphere.



Generalized: networks across both hemispheres.



Unknown whether focal or generalized (Example: EEG comes back normal, but seizure activity is taking place)



Unclassified due to inadequate information (not witnessed or no test results such as an EEG or MRI)

Focal seizures (involve one area of the brain)

Focal Seizures with Preserved Consciousness (simple partial seizures)

- No loss of consciousness; often experience an aura
- Changes in emotions (sudden fear or joy)
- Senses altered (changes in smell, feel, taste, sound, or how things look)
- Tingling
- Dizziness
- Flashing lights
- Can result in the jerking of a body part

Focal Seizures with Impaired Consciousness (complex partial seizures)

- May stare and not respond
- May laugh/scream for no apparent reason
- Perform repetitive movements (hand rubbing, lip smacking, chewing, walking around.
- Mumble
- May appear as if under the influence of drugs/alcohol (cannot comply/follow an order)

Generalized Seizures (involve all areas of the brain)

Absence Seizures (petit mal) Typically occur in children Stare into space without movement Eye blinking/lip smacking May occur in clusters (as much as 100 times a day), causing brief loss of awareness	**Tonic Seizures** Causes stiff muscles and may alter consciousness. Affects muscles in the back, arms and legs, and can cause the person to fall.	**Atonic Seizures** Also called drop seizures, they cause a loss of muscle control. Most often affect the legs.
Clonic Seizures Cause repeated rhythmic jerking muscle movements. Usually affect the neck, face, and arms.	**Myoclonic Seizures** Appear as sudden, brief jerks or twitches. Usually affect the upper body, arms, and legs.	**Tonic-Clonic (grand mal)** Causes a sudden loss of consciousness, body stiffening, twitching, and shaking. Can cause a loss of bowel/bladder function.

How is epilepsy diagnosed?



History and witness descriptions guide evaluation.



EEG assesses electrical activity; video-EEG may capture events.



MRI or CT can reveal structural changes.



A normal routine EEG does not rule out epilepsy.

Treatment is individualized



Antiseizure medicines are the most common treatment.



Surgery, devices (VNS, RNS, DBS), or supervised dietary therapy (Keto diet) may help.



Report ongoing seizures and difficult side effects. It is important to keep a journal regarding seizures, triggers, and symptoms. Both physical and mental symptoms are important.



Do not stop medicine suddenly without clinical guidance.

Everyday management

Medication



Many people with epilepsy can forget to take their meds. Setting a reminder (apps), keeping a journal, using a pill box are just a few ways to remember to take medication.

Mental Health



Seeing a therapist helps to reduce anxiety, depression and other mental health complications. For some, seeing a psychiatrist is essential to maintain good health.

Stress Relief



Stress is a trigger for many people who have epilepsy. Walking, hiking, yoga, meditation, being with friends, are just a few examples of what people can do to reduce stress.

Nutrition



Some people with epilepsy follow a keto diet to control seizures. It is important to eat well, reduce processed foods, limit sugar and caffeine intake to prevent seizures.

Sleep



Getting a good night's sleep and plenty of rest is important for people with epilepsy. Sleep deprivation is a trigger for some people with epilepsy.

Exercise



Exercise is very beneficial for people with epilepsy. Exercise helps to reduce stress, improve flexibility, maintain a healthy weight and improve quality of life.

Seizure First Aid Tonic-Clonic Seizure

1. Stay calm; your goal is to keep the person safe. Make sure there are no items near them. Have others help to clear the area if needed.

2. Have someone start timing the seizure. Turn the person on their side. Put a pillow or something soft under their head to prevent injury.

3. Remove any glasses they have; loosen clothing (necktie) to make sure breathing is not restricted. Do what you can to comfort them and assure them things are ok.

4. If seizure does not end in 5 minutes, repeats, or the person does not return to their normal state, call 911 for medical help.

NOTE: Not all seizures require medical emergency assistance



Seizure First Aid Focal Seizure

1. If the person is aware of what is going on, stay with them and assure them things are ok. They may show signs of fear, confusion, or be experiencing dizziness.

2. If the person becomes impaired, the goal is to keep them safe. If they are walking around, make sure they do not walk off to where they can get injured (parking lot). If others are there, ask for help. Do not leave the person alone.

3. Focal seizures can last, on average, 1-3 minutes. The person afterward may come off as confused or tired. They may have a headache or feel nauseated.

4. If the person has another seizure or does not return to their normal state, call 911 for medical help.

NOTE: Not all seizures require medical emergency assistance



What to avoid



Do not restrain movements; you can cause injury. Some people can become aggressive or combative if you restrain them.



Put NOTHING in their mouth. There is a myth that people having a seizure can swallow their tongue. They cannot.



Wait until fully alert before offering food or drink.



Give prescribed rescue treatment only as directed and trained. Some people may have a nasal spray or dissolvable tablet as a form of rescue treatment. For those with a seizure action plan, it is important to list this.

When to call 911



A seizure lasts more than 5 minutes



Repeated seizures without recovery, breathing trouble, or serious injury.



A seizure in water or a first known seizure.



Pregnancy, or diabetes with loss of consciousness.

Support recovery



- Stay with them and reassure them that things are ok
- Document the seizure- what type, how long, and whether medical attention was needed
- Some people recover in a short time, while others may need to sleep to recover
- Make sure the person has recovered before offering them any food or drink

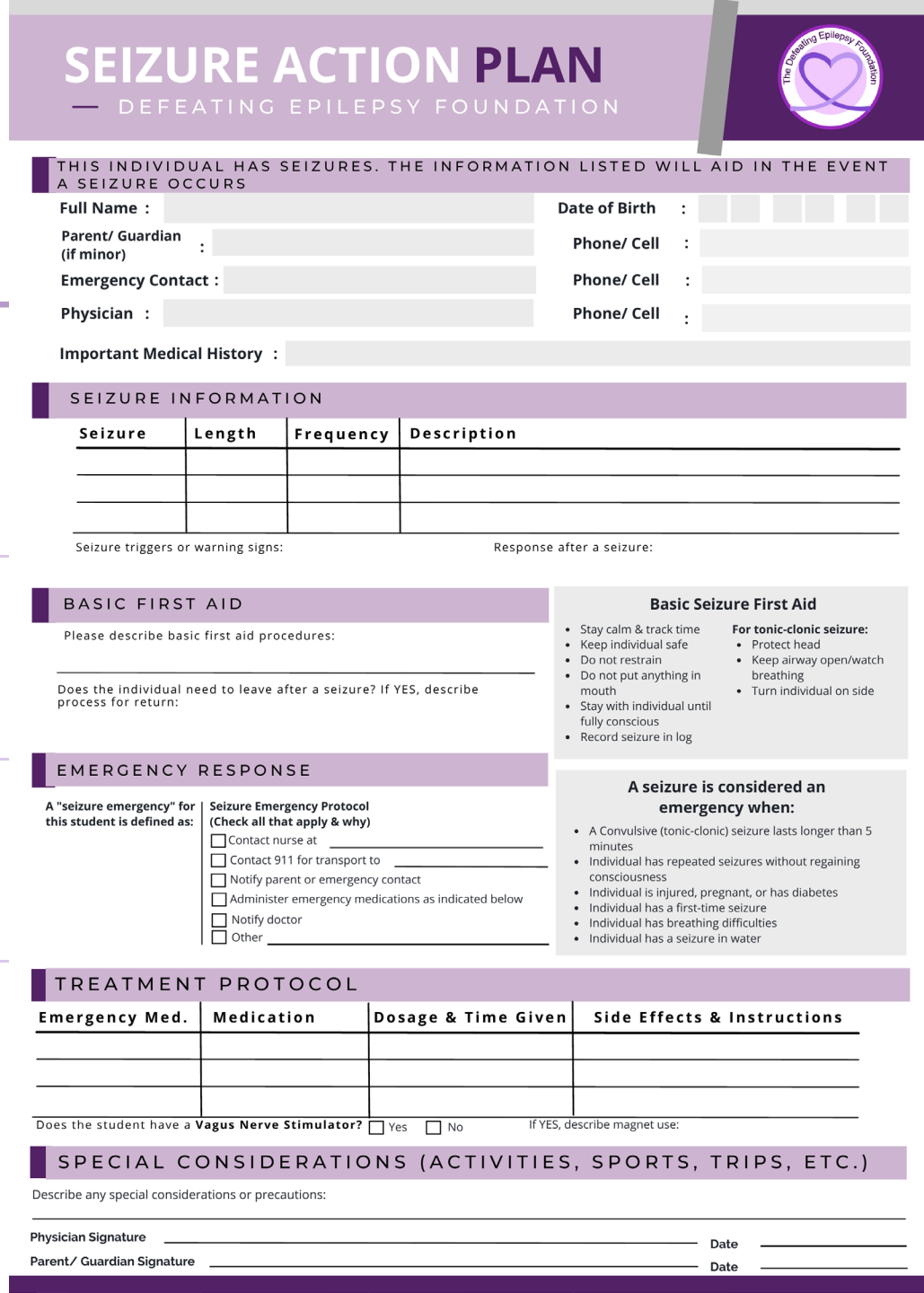
Seizure Action Plan

Describes usual seizures and recovery.

Lists first aid, emergency criteria, and contacts.

Includes prescribed rescue treatment, if needed.

Develop and review it with the treating clinician.



SEIZURE ACTION PLAN

— DEFEATING EPILEPSY FOUNDATION

THIS INDIVIDUAL HAS SEIZURES. THE INFORMATION LISTED WILL AID IN THE EVENT A SEIZURE OCCURS

Full Name : **Date of Birth :**

Parent/ Guardian (if minor) : **Phone/ Cell :**

Emergency Contact : **Phone/ Cell :**

Physician : **Phone/ Cell :**

Important Medical History :

SEIZURE INFORMATION

Seizure	Length	Frequency	Description

Seizure triggers or warning signs:

Response after a seizure:

BASIC FIRST AID

Please describe basic first aid procedures:

Does the individual need to leave after a seizure? If YES, describe process for return:

Basic Seizure First Aid

- Stay calm & track time
- Keep individual safe
- Do not restrain
- Do not put anything in mouth
- Stay with individual until fully conscious
- Record seizure in log

For tonic-clonic seizure:

- Protect head
- Keep airway open/watch breathing
- Turn individual on side

EMERGENCY RESPONSE

A "seizure emergency" for this student is defined as:

Seizure Emergency Protocol (Check all that apply & why)

- ☐ Contact nurse at
- ☐ Contact 911 for transport to
- ☐ Notify parent or emergency contact
- ☐ Administer emergency medications as indicated below
- ☐ Notify doctor
- ☐ Other

A seizure is considered an emergency when:

- A Convulsive (tonic-clonic) seizure lasts longer than 5 minutes
- Individual has repeated seizures without regaining consciousness
- Individual is injured, pregnant, or has diabetes
- Individual has a first-time seizure
- Individual has breathing difficulties
- Individual has a seizure in water

TREATMENT PROTOCOL

Emergency Med.	Medication	Dosage & Time Given	Side Effects & Instructions

Does the student have a **Vagus Nerve Stimulator?** ☐ Yes ☐ No

If YES, describe magnet use:

SPECIAL CONSIDERATIONS (ACTIVITIES, SPORTS, TRIPS, ETC.)

Describe any special considerations or precautions:

Physician Signature **Date**

Parent/ Guardian Signature **Date**

Seizure Action Plan Importance

Keep Things Updated

Make sure all information is current and correct. Have the neurologist/epileptologist review the Seizure Action Plan and approve it.

Enforcing the Plan

For kids in school, it is important for faculty and staff to be trained in seizure first aid. An emergency plan needs to be in place, so faculty and staff know how to act and what to do if a seizure takes place.

For adults, it is just as important. Employers need to put a plan into place if an employee has epilepsy as well as having seizure first aid training.

Don’t be Afraid to Ask Questions

It is important to ask questions if you do not understand something. Make sure everyone is on the same page when it comes to the plan.

Request Training if Needed

For teachers and professionals who have not been trained in seizure first aid or are not familiar with Seizure Action Plans, please reach out to The Defeating Epilepsy Foundation for training at info@defeatingepilepsy.org or call 909-740-4461.



Mental Health

- Individuals with epilepsy have higher rates of mental health challenges such as anxiety, depression, and PTSD. They also have a higher rate of suicidal ideation.
- Many individuals with epilepsy can also be neurodivergent and need to take different approaches to problem-solving and communication.
- Creating a positive environment, without stigma or judgement, is important for individuals with epilepsy. Isolation and judgement can create a negative impact on their overall wellness.
- It is important for caregivers of individuals with epilepsy to receive support as well. Many caregivers experience burnout.



Take understanding into action

- Recognize that seizures can look different.
- Protect, stay, time, and know emergency signs.
- Build a clinician-guided action plan.
- Offer respect, support, and access to care.

Thank you for attending today!

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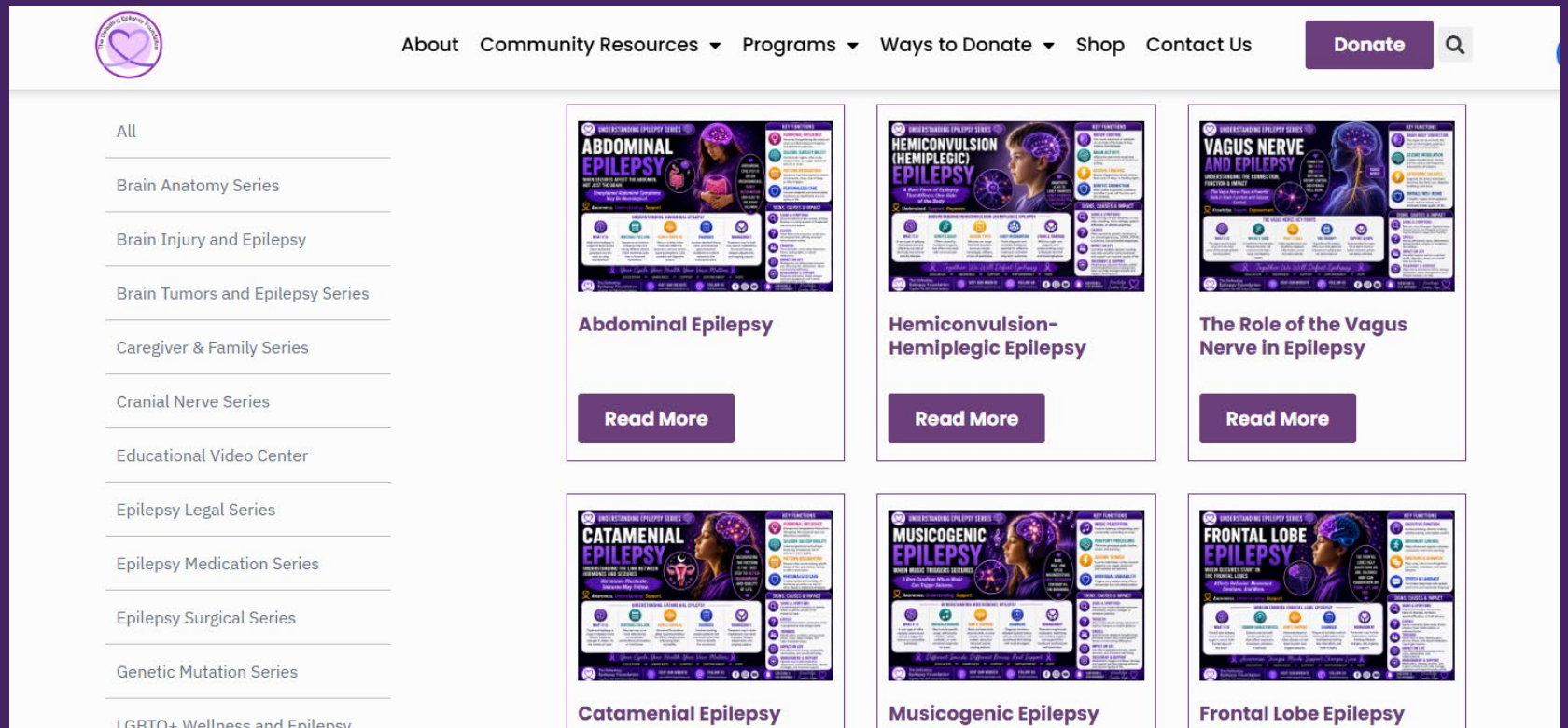
Phone: (909) 740-4461

Social Media: @defeatepilepsy

Check out our educational library to learn about different types of epilepsy, seizures, parent resources and more!

https://www.defeatingepilepsy.org/epilepsy-education-library/

Go to community resources, and click on educational library



Resources

International League Against Epilepsy (2024). Unknown Onset Seizure. *International League Against Epilepsy.* Retrieved from: https://www.epilepsydiagnosis.org/seizure/unknown-onset-groupoverview.html

Mayo Clinic (2025). Epilepsy: Symptoms and Causes. *Mayo Clinic.* Retrieved from: https://www.mayoclinic.org/diseases-conditions/epilepsy/symptoms-causes/syc-20350093