

# National Epilepsy Education and Awareness Collaborative

## Disparities in Epilepsy Care

Chi Eta Phi Nursing Sorority Boule  
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# LEARNING OBJECTIVES

- Introduce epilepsy and its signs and symptoms in a public health context
- Highlight epilepsy and comorbidities related to selected populations
- Examine how seizure recognition, response and first aid saves lives
- Identify educational resources for people with epilepsy
- Describe how physicians and healthcare providers may support people with epilepsy

# The Need for Increased Epilepsy Awareness

- During some seizures, people may exhibit behaviors that affect their awareness, behavior or ability to communicate
- Seizures may:
  - Be subtle and difficult to recognize
  - Mimic other conditions
  - Place a person in danger
  - Require first aid or emergency medical care
  - Can result in death



# THE EPILEPSY FOUNDATION

- National agency dedicated to the welfare of the over 3 million people with epilepsy in the U.S. and their caregivers.
- Mission: To lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures and save lives.
- Network of 50 local Epilepsy Foundation affiliates and chapters around the country.
- Services and programs support and educate anyone affected by epilepsy.
- For more information visit [www.epilepsy.com](http://www.epilepsy.com).

# SEIZURES AND EPILEPSY ARE COMMON

- **3.4 million** Americans have active epilepsy
- 1 in 26 people will develop epilepsy
- 1 in 10 people will have a seizure in their lifetime
- **4<sup>th</sup> most common neurological disorder** in the U.S.
  - Vastly underdiagnosed and misdiagnosed

Epilepsy can happen at any age, but start most often in **young children** and **older adults**

- In adults, the most common causes of epilepsy are head trauma, stroke, or tumor
- Focal seizures are the most common type in adults newly diagnosed with epilepsy



# BURDEN OF EPILEPSY

- **Annual cost:** ~ \$15.5 billion from health care costs and loss of employment, wages and productivity <sup>1</sup>
  - \$9.6 billion/year – direct medical costs<sup>2</sup>
  - Highest direct costs associated with initial onset and diagnosis<sup>1,3</sup>
  - All costs higher for people with refractory epilepsy
- **Quality of life:** Individual and family impact
- **Seizure control:** 30-40% of people with persistent seizures, adverse effects despite medical treatment<sup>1</sup>
- **Mortality:** Each year, 25,000 to 50,000 die of seizures and related causes<sup>1</sup>

<sup>1</sup>IOM 2012. Epilepsy across the spectrum: Promoting health and understanding.

<sup>2</sup>Yoon, D. et al.. Epilepsia 2009;50(10):2186-91

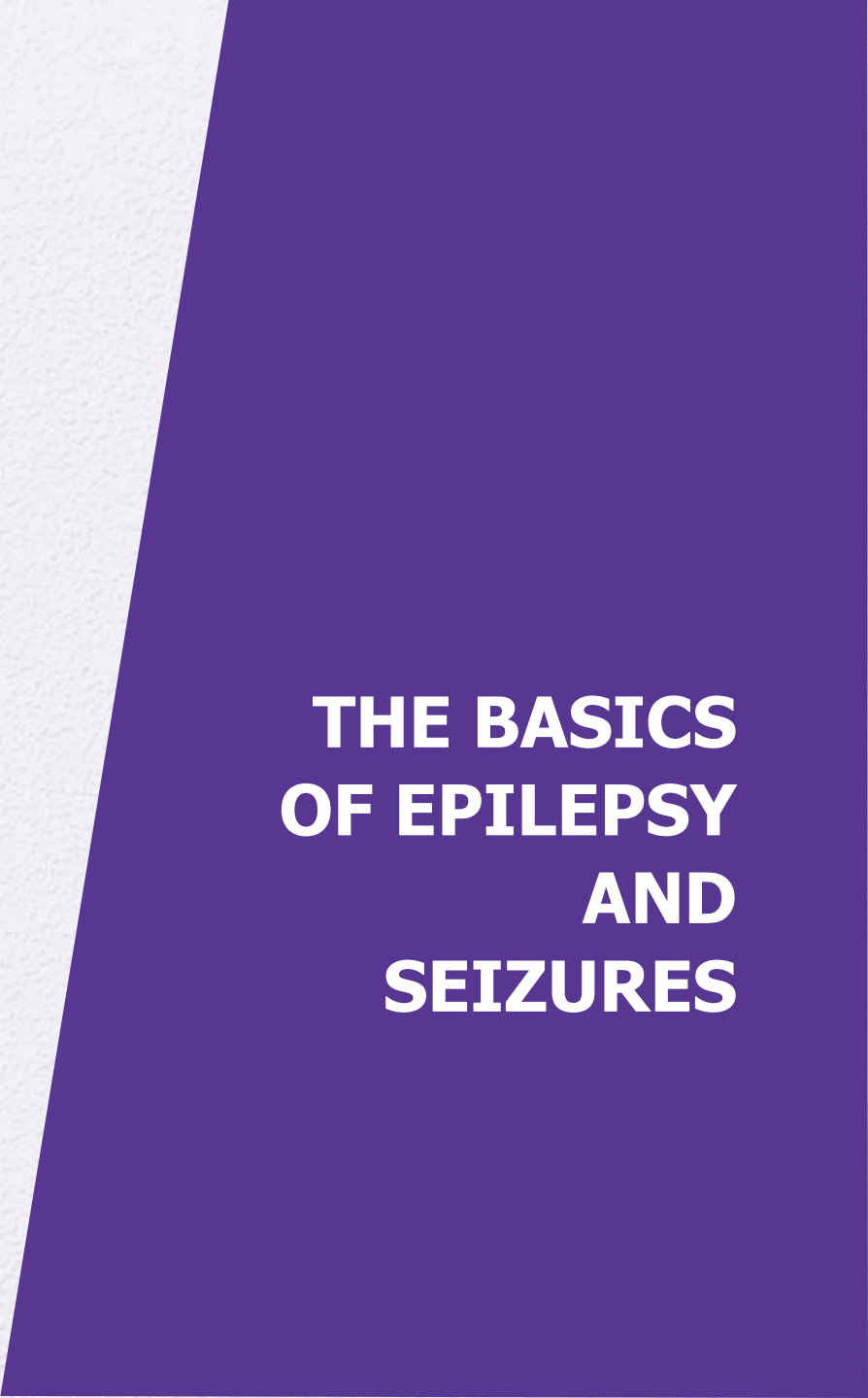
<sup>3</sup>Begley CE et al. Epilepsia 2000;41(3):342-51

# Epilepsy is More Common Than You Think

**136,000  
Illinoisans  
currently have  
Epilepsy**



**~19,500 African American Illinoisans**



# **THE BASICS OF EPILEPSY AND SEIZURES**



# SEIZURES – WHAT ARE THEY?

## A seizure is...

- Symptom of a problem in the brain
- Sudden surge of abnormal electrical activity, may involve complex chemical changes in brain cells
- Can be symptom of other medical problems
  - Provoked seizures
  - Unprovoked seizures



# EPILEPSY – WHAT IS IT?

- Not a single entity or disease but a family of syndromes
- Defined as:
  - 2 or more unprovoked seizures > 24 hours apart
  - 1 seizure with risk of more seizures
  - Diagnosed with an epilepsy syndrome
  - Tendency to have unprovoked recurring seizures, not caused by any known medical condition
- The term “epilepsy” = “seizure disorder”

# Two Major Groups of Seizures

- Provoked
  - Seizure provoked by an acute insult or injury to the brain
  - Seizures do not recur after the acute illness has resolved
- Unprovoked
  - Seizures may recur without an *immediate* provoking cause
  - Tendency to recurring unprovoked seizures is epilepsy



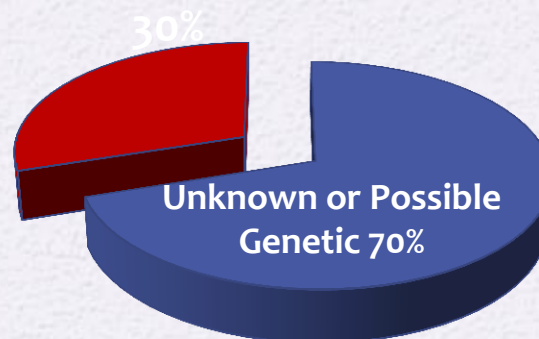
# Factors That May Provoke Seizures

- Very high fever
- Drug use, alcohol withdrawal
- Lack of oxygen to the brain (ie. near drowning)
- Head injury
- Brain tumor, infection, stroke
- Dehydration or hyper hydration
- Complication of diabetes, pregnancy, or other acute medical illnesses

# Causes of Epilepsy

- Brain injury at birth
- Brain lesions (tubers, tumors)
- Congenital malformations
- Past head injury, trauma, stroke
- Infections of the brain (meningitis, encephalitis)
- Metabolic problems
- Other neurological conditions

## Symptomatic



# Early Death in Epilepsy

- Causes of early death
  - Status epilepticus
  - Complications of seizures
  - Accidents and drowning
  - Drug reactions
  - Suicide
  - SUDEP
- SUDEP - Sudden Unexpected Death in person with Epilepsy
  - No obvious cause for death
  - Affects 1 of 1,000 people in U.S. each year
  - Highest risk in people with uncontrolled seizures, > 3 tonic-clonic seizures a year, seizures at night



# Seizure Triggers

- Missed or late medication (#1 reason)
- Stress/anxiety
- Lack of sleep/fatigue
- Hormonal changes
- Illness
- Alcohol or drug use
- Drug interactions
- Overheating/overexertion
- Poor diet/missed meals
- Extreme heat/cold temperatures
- Certain smells
- Flashing lights, photic or other stimulation with reflex epilepsy



## TYPES OF SEIZURES

# Did You Know That...

- Most seizures are NOT medical emergencies
- People may NOT be aware they are having a seizure and may NOT remember what happened
- Epilepsy is NOT contagious
- Epilepsy IS a medical illness, just like asthma or diabetes
- It is rare for a person to die during a seizure
- A person can NOT swallow his/her tongue during a seizure



# Types of Seizures

- Generalized Seizures
  - Begins in both sides of brain
  - Loss of consciousness assumed
- Focal Seizures
  - Begins in one part or side of brain
  - Consciousness may or may not be affected
  - May spread to a generalized seizure
- Unknown Onset
  - Beginning of seizure not known



*“The type of seizure depends on where the abnormal activity happens in the brain and how much of the brain is involved”*

# Features of Seizures

## Generalized seizures

- Motor
  - Tonic-clonic (stiffening, jerking)
  - Atonic
  - Clonic
  - Myoclonic
  - Tonic
- Non-Motor
  - Absence
  - Atypical absence

## Focal seizures

- Based on consciousness
  - Aware
  - Impaired Awareness
- Based on movement
  - Motor
  - Non-motor
- Other features
  - Sensory
  - Cognitive/emotional
  - Autonomic

# A Seizure May Appear As:

- A sudden cry and fall, followed by
  - Generalized stiffening of all limbs
  - Convulsive movements of all limbs
  - Shallow/interrupted breathing
  - Loss of bowel/bladder control
  - Slow return to consciousness
  - May be confused, tired, headache afterwards

Known as a **generalized tonic-clonic seizure** or  
convulsion



## Or A Seizure Can Be...

- Blank staring, chewing, other repetitive purposeless movements (automatisms)
- Wandering, running
- Confused or no recall of event
- Unable to talk or incoherent speech
- Crying, screaming
- Change in muscle tone or movements
- May fall

Known as a **focal seizure with impaired awareness**

# A Focal Onset Seizure May Be Mistaken For:

- Drunkenness
- Illegal drug use
- Medical conditions such as a stroke or diabetic reaction
- Signs of mental illness

## A Person Having A Focal Seizure With Impaired Awareness Is:

- Unaware of their actions, unable to control body movements
- Unable to respond to questions or directions from others
- May not be capable of organized thought

*Clumsy, undirected agitated resistance is possible when an individual is restrained during a seizure or in the period of confusion following a seizure*



# Michael's Story



# SeizureFirstAid

What to do in the event of a seizure

1

**STAY** with the person and start timing the seizure.  
Remain **calm** and check for medical ID.



2

Keep the person **SAFE**.  
Move or guide away from **harmful objects**.



3

Turn the person onto their **SIDE** if they are not awake and aware. **Don't block airway**, put something small and soft under the head, loosen tight clothes around neck.

4

Do **NOT** put **anything** in their mouth.  
Don't give water, pills or food until the person is awake.



5

Do **NOT** **restrain**.



6

**STAY** with them until they are awake and alert after the seizure.  
**Most seizures end in a few minutes.**



**Call 911:**

- ▲ Seizure lasts longer than 5 minutes
- ▲ Repeated seizures
- ▲ Difficulty breathing
- ▲ Seizure occurs in water
- ▲ Person is injured, pregnant, or sick
- ▲ Person does not return to their usual state
- ▲ First time seizure

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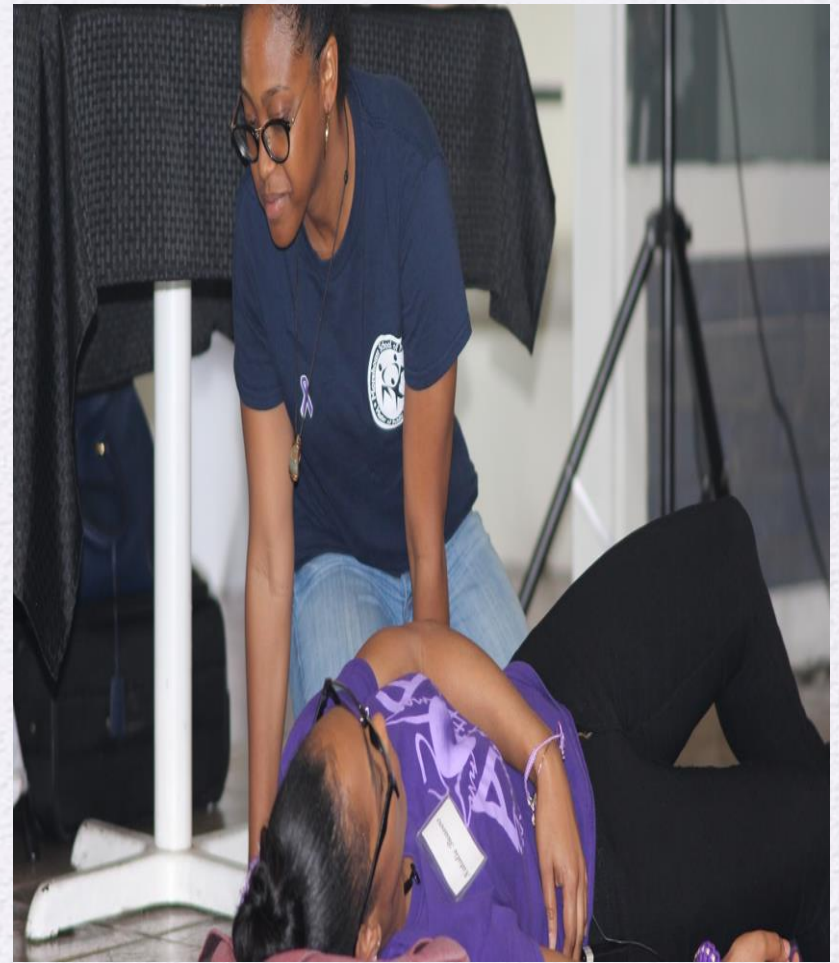
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## SEIZURE FIRST AID:

**RECOGNITION AND RESPONSE**





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# SEIZURE FIRST AID:

## *RECOGNITION AND RESPONSE*

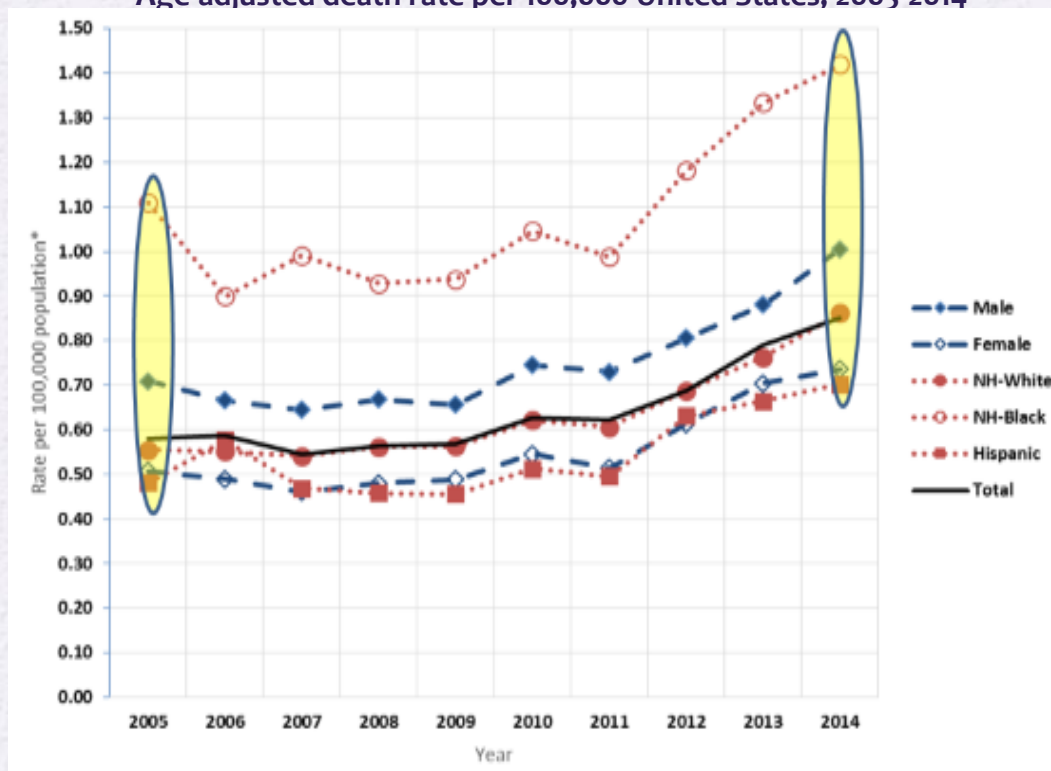


# **EPILEPSY DISPARITIES**

# Epilepsy as a Listed Cause of Death

## Significantly Increased Since 2005

Age-adjusted death rate per 100,000 United States, 2005-2014



Greenlund et al, Epilepsy & Behavior, 2017  
Owens, Epilepsy & Behavior, 2017

# Epilepsy and African Americans

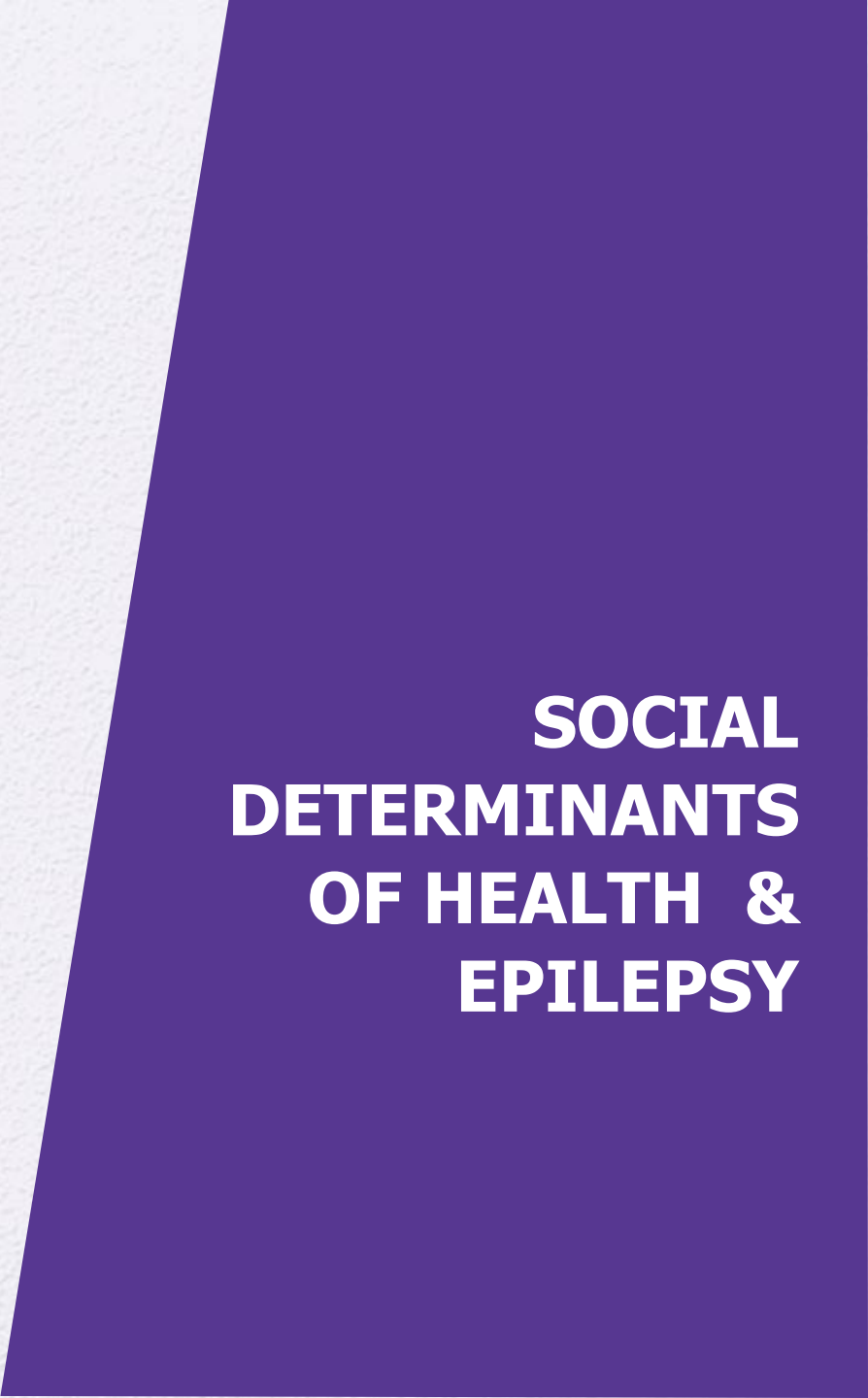
- According to the U.S. Census Bureau and the Centers for Disease Control and Prevention, **637,000** African Americans have been told by a physician or health care professional that they had epilepsy or a seizure disorder.
- About **375,000** African Americans have active epilepsy, which means they have been told they have epilepsy or a seizure disorder and are taking seizure medication or had at least one seizure in the past year.
- Over **20,000** African Americans are diagnosed with seizures or epilepsy each year.



# Epilepsy and African Americans

African Americans are also:

- More likely to be diagnosed with epilepsy in an emergency room than white Americans\*
- More likely to develop epilepsy over a lifetime (called lifetime prevalence) than white Americans\*
- Likely to experience status epilepticus, a medical emergency in which a seizure continues for 10 minutes or more without stopping



# **SOCIAL DETERMINANTS OF HEALTH & EPILEPSY**

# Epilepsy and Social Determinants of Health

- Employment
- Transportation
- Food Insecurity
- Access to Care
- Poverty

**EPILEPSY** CAN  
MAKE IT HARD  
TO HAVE A **JOB**



**32%** of adults with epilepsy vs  
**7%** without epilepsy  
**CAN'T WORK**



**29%** of adults with epilepsy vs  
**8%** without epilepsy  
**CAN'T USE A CAR OR PUBLIC  
TRANSIT TO GET PLACES**

[CDC.gov/epilepsy](https://www.cdc.gov/epilepsy)

**336,000 KIDS**  
HAVE AT LEAST  
ONE **SEIZURE**  
ANNUALLY



**4 in 10**  
live in homes at or close  
to the poverty level



**3 in 10**  
live in homes without  
enough food

[CDC.gov/epilepsy](https://www.cdc.gov/epilepsy)



**13%** of adults  
with epilepsy

**3%** of adults  
without epilepsy

FELT **NERVOUS,**  
**SAD, OR HOPELESS**  
IN THE PAST 30 DAYS

[CDC.gov/epilepsy](https://www.cdc.gov/epilepsy)

**PAYING FOR  
HEALTH CARE**  
IS HARD FOR PEOPLE  
WITH **EPILEPSY**



**Medicines**  
**21%** of adults with epilepsy vs  
**9%** without epilepsy



**Eye Glasses**  
**18%** of adults with epilepsy vs  
**8%** without epilepsy



**Dental Care**  
**27%** of adults with epilepsy vs  
**14%** without epilepsy

PEOPLE REPORTING  
**GOOD OR BETTER  
MENTAL HEALTH**

**54%**

People with a history of epilepsy

**79%**

People without a history of epilepsy

**80%**

Healthy People 2020 target

[CDC.gov/epilepsy](https://www.cdc.gov/epilepsy)





# RESOURCES

# How can XHO Nurses help?

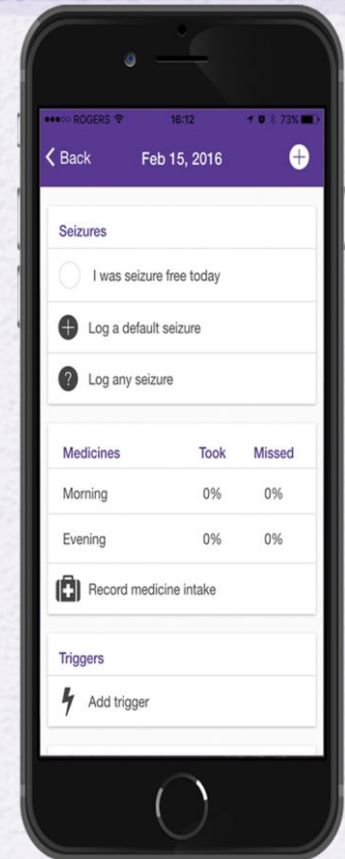
Nurses can help people/families with epilepsy by:

- Incorporating epilepsy messaging into existing chronic disease promotion and education
- Make timely referrals / Project ECHO
- Dispelling myths about epilepsy
- Knowing and using correct seizure first aid
- Decreasing stigma
- Learning about comorbidities and epilepsy /screen
- Connect with providers offering epilepsy **self-management programs**
- Facilitating connections to community services /local Foundation office

# Epilepsy Resources

For more information visit [epilepsy.com](http://epilepsy.com)

- Home Based Self-Management & Cognitive Training Changes Lives **HOBSCOTCH**
- **Project UPLIFT** - Using Practice and Learning to Increase Favorable Thoughts
- Program of Active Consumer Engagement in Epilepsy Self-management – **PACES for Epilepsy**
- **Project ECHO** (Extended Health Care Outreach) for providers that treat adult people with epilepsy
- National **Wellness Institute, Learning Healthcare Systems**
- Find seizure tracking tools - **My Seizure Diary, Texting4Control**





# CALL TO ACTION

Centers for Disease Control and Prevention

## MMWR

## WHEN SEIZURES DON'T STOP

### EPILEPSY IS COMMON

**3 MILLION U.S. ADULTS**  
HAVE ACTIVE EPILEPSY



**56% OF ADULTS**  
WITH EPILEPSY STILL  
HAVE SEIZURES

### A SPECIALIST CAN HELP STOP SEIZURES

**1 OUT OF 3 ADULTS WITH EPILEPSY**  
DIDN'T SEE A SPECIALIST IN  
THE PAST YEAR



### ADULTS WITH UNCONTROLLED SEIZURES SHOULD



**SEE AN EPILEPSY  
SPECIALIST**



**TAKE MEDICINE  
AS PRESCRIBED**



**LEARN TO MANAGE  
EPILEPSY**



**CALL EPILEPSY  
FOUNDATION HELPLINE  
1-800-332-1000**

Data as of 2015 as published in Tian et al. *MMWR*. April 2018  
<https://go.usa.gov/xQjSw>

**WWW.CDC.GOV**

# Contact Information

## **Epilepsy Foundation**

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

### **Epilepsy Foundation of Greater Chicago**

17 N. State Street Suite 650

Chicago, IL 60602

312-939-8622

800-273-6027

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

### **Epilepsy & Seizures 24/7 Helpline**

1-800-332-1000

en Español 1-866-748-8008

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

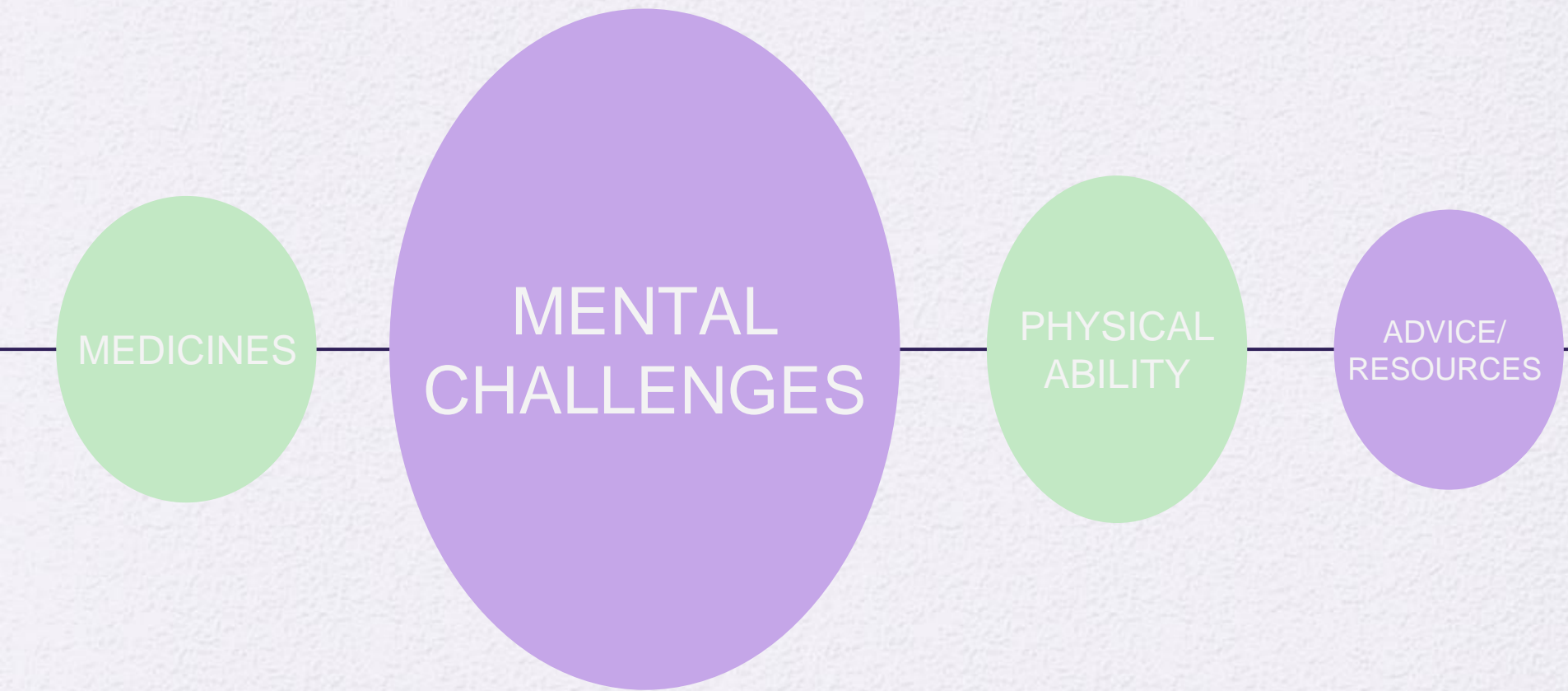
# Personal Story: Ronald James





What providers should know  
about epilepsy survivors?

# Communication with the patient/family



# EPILEPSY & MENTAL ILLNESS

The diagnosis of depression, anxiety, and other mental illnesses are at an increase to those living with epilepsy.

Having this brain disorder affects emotions and behavior.

It is very important for doctors, nurses, or assistants to ask questions about changes in behavior or thoughts.

Many teens dealing with epilepsy are at a high risk of battling depression or a mental illness.





## EPILEPSY & MENTAL ILLNESS

- Depression and Anxiety
- Emotions and Behavior
- Healthcare Visit
- Teens Issues





# ADVOCACY AND SUPPORT

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# THANK YOU

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**Epilepsy Foundation**  
**www.epilepsy.com**  
**Epilepsy & Seizures 24/7 Helpline**  
**800.332.1000**