# THE GOAL

PAUSE to Learn Your Epilepsy aims to empower people with epilepsy (PWE) to improve management of their disease, communication with their health care providers, and their quality of life.

# REASONING BEHIND PAUSE



Self-management education may improve quality of life and health outcomes among people with chronic conditions by reinforcing healthy behaviors & SM skills.



Set personalized goals and achieve them through action plans.



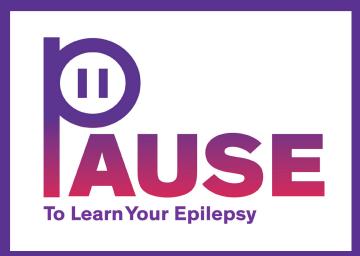
Improve medication adherence, self-efficacy, and confidence.



Reduce seizure frequency, hospitalizations, and ER visits.



Increase knowledge and improve communication skills





#### WHAT IS PAUSE?

PAUSE (Personalized Internet Assisted Underserved Self-Management of Epilepsy) to Learn Your Epilepsy is designed to help people living with epilepsy (PWE) learn and apply skills to manage epilepsy and its effects on quality of life. PWE and their healthcare team, or PWE and their case managers, determine PWE's self-management learning needs, identify goals, and determine an action plan. An internet-connected computer tablet is pre-programmed to provide targeted self-management education and is loaned to participants at no cost for 8-12 weeks. During this time, participants will learn, at their own pace, how to better self-manage their epilepsy through education modules on the tablet. Participants also have the option of 10-15 minute one-on-one video calls with PAUSE education coordinator to reinforce education and provide assistance.



### WHO WE ARE

PAUSE was developed by researchers and epileptologists at University of Illinois at Chicago (UIC). PAUSE is implemented through the UIC Health Clinic and through case managers at the Epilepsy Foundation of Greater Chicago (EFGC). The PAUSE study is supported by a grant funded by the Center for Disease Control and Prevention.



## PROGRAM STRUCTURE

- PWE complete enrollment questionnaire and forms.
- PWEs and their healthcare team/PWEs and their case managers identify selfmanagement learning needs, set goals, and develop an action plan.
- Participants are loaned a tablet for 8-12 weeks to complete self-management education modules.
- 10-15 minute weekly video calls with PAUSE education coordinator (recommended).
- Follow-up questionnaires 3-months, 6-months, and 12-months after return of tablet and education completion questionnaire.

# DESIRED OUTCOMES

- Set personalized goals and achieve them through action plans
- Increase self-management practice, behavior, skills and confidence
- Reduce seizure frequency, hospitalizations, and ER visits
- Improve quality of life

# **MEASURES**



Epilepsy SM practice (AESMMI-65)



Epilepsy Self-efficacy scale



Epilepsy outcome expectancy scale



Personal impact of epilepsy (PIES)



Quality of life (QOLIE-10)

# **PAUSE Contacts**



Dilip Pandey MD, PhD (UIC) 312-413-1882

pause@uic.edu



http://managingepilepsywell.org





## PARTICIPANT REQUIREMENTS

- English-speaking PWE (over 18 years of age) who have been diagnosed with epilepsy.
- · Free of cost
- Participants must have access to a telephone.
- Does not require travel outside of regular clinic visits.
- All PAUSE participation can be completed over the telephone or through the mail.



### PROGRAM COMPONENTS

Epilepsy self-management learning modules were developed in consultation with associate editor of epilepsy.com

- Epilepsy Self-Management
- Types of Seizures
- Recognizing Seizures
- Seizure observation and recording
- Tips for lifestyle management
- Seizure first aid
- · Seizure response plans
- Effects of Epilepsy
- Epilepsy medications and adherence
- Surgery and devices



## LENCTH OF THE PROGRAM

- Participants are loaned a tablet for 10-12 weeks to complete self-management education modules
- 10-15 minute weekly video calls with PAUSE education coordinator (recommended)
- Follow-up questionnaires 3-months, 6-months, and 12-months after return of tablet and education completion questionnaire



#### **EVALUATION**

PAUSE is currently under development and is being tested.

PAUSE is being tested for feasibility & efficacy to see if it:

- Improves PWE compliance with medication regimens
- Increases overall knowledge about epilepsy
- Increases self-efficacy and epilepsy self-management
- Increases the ability to set and achieve SM goals
- Reduced seizure frequency and emergency room visits
- Improves quality of life

#### **REFERENCES**

- Zack, M. M. (2017). National and state estimates of the numbers of adults and children with active epilepsy—United States, 2015.MMWR. Morbidity and mortality weekly report, 66.
- Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. Patient education and counseling, 48(2). 177-187