

**PAUSE**

To Learn About Your Epilepsy



**Illinois Prevention  
Research Center**

# **Managing Epilepsy Well (MEW)**

## **Network Collaborating Center – PAUSE to Learn Your Epilepsy**

**DILIP K. PANDEY, MD, PhD, FAHA**

Principal Investigator/Associate Professor, Neurology and Rehabilitation

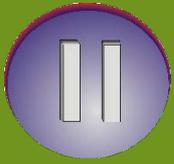
**JEFFERY A. LOEB, MD, PhD**

Co-Principal Investigator/ Professor and Head, Neurology and Rehabilitation

Overview of MEW Network Collaborating Center at the UIC

Chicago, IL

Date: May 11, 2015



**PAUSE**

To Learn About Your Epilepsy

# THE PROBLEM

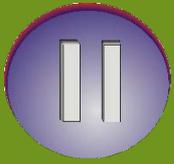
**Patients with epilepsy have varying needs for self-management and varying abilities to participate in self-management programs due to comorbidities.**

- **Aims**

- **Develop and test an internet assisted learning tool, optimize the approach on patients with varying degrees of comorbid and socioeconomic impairments (with and without a caregiver), and optimize the web-based self-management modules.**
- **Implement and perform an outcome analysis of the epilepsy self-management system both in our specialty clinics as well as in people with epilepsy from the community through our local Epilepsy Foundation of Greater Chicago.**



**Illinois Prevention  
Research Center**



**PAUSE**

To Learn About Your Epilepsy

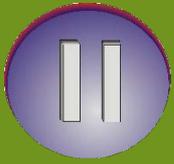
# THE CHALLENGE

How to create a ‘personalized’ system and measure outcomes for a wide spectrum of patients with different needs.

- **The Approach**
  - Tablet device with built in 4G and web conferencing with a dedicated educator who develops a personalized plan for each patient.



**Illinois Prevention  
Research Center**



**PAUSE**

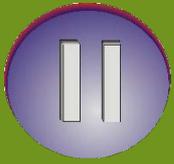
To Learn About Your Epilepsy

# OVERVIEW

- **PAUSE = Personalized internet Assisted Underserved Self-management of Epilepsy**
- **PAUSE integrates 5 key features to improve self-management behaviors and skills:**
  - collaborative care in making health care decisions, and goal setting
  - self-management education for PWE by personalized internet-assisted approach using publically available web-based resource
  - learning how to use web-based Epilepsy self-management education at a self-regulated pace
  - on-line training sessions and support from an educator, and
  - involvement of family/care-takers in learning to use epilepsy self-management skills to improve how they provide support.
- Collaborative care combined with personalized internet-assisted approach using publically available web resource is innovative and may help to motivate people with epilepsy to improve self-management behaviors and work towards better health and quality of life.



**Illinois Prevention  
Research Center**



# PAUSE

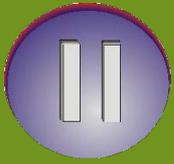
To Learn About Your Epilepsy

# OVERVIEW

- **The goal setting** ask the patient to identify specific approaches they plan to take to address the problem as well as a time frame
  - Goals are mutually agreed goals identified by providers (physician, nurse) and patient.
  - Reminders will be sent to the patient electronically so they can self-assess progress.
- **Overall goal:**
  - develop, test, optimize, and implement personalized web-based self-management curricula with real-time assistance by an educator targeting adult people with epilepsy (PWE) and
  - perform an outcome analysis to examine study hypothesis:
    - **Primary Hypothesis:** Internet assisted personalized self-management for epilepsy will improve medication compliance, knowledge about epilepsy, self-efficacy and epilepsy self-management; and reduce seizure frequency and emergency room visits.
    - **Secondary Hypothesis:** Internet assisted personalized self-management for epilepsy will significantly improve quality of life of adult PWE.



**Illinois Prevention  
Research Center**



**PAUSE**

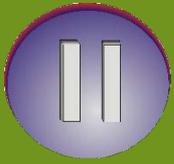
To Learn About Your Epilepsy

# OVERVIEW

- **Study population - participants will be recruited from**
  - UI Health Epilepsy Clinic (phase II)
  - From community through referrals from the EF local chapter EFGC (phase III)
- **Intervention – use of self-management education modules already developed by the Epilepsy Foundation at the epilepsy.com web site combined with real-time assistance from an educator for 10-12 weeks.**
- **Assessments –**
  - Baseline
  - Completion of intervention
  - 90 days after intervention
  - 180 days after intervention



**Illinois Prevention  
Research Center**



**PAUSE**

To Learn About Your Epilepsy

# OVERVIEW

- **Measures:**
  - Medication adherence
  - Epilepsy Outcome Expectancies
  - Epilepsy Self-efficacy
  - Personal Impact of Epilepsy
  - PHQ-9
  - Seizure frequencies
  - ER visits



**Illinois Prevention  
Research Center**

The screenshot shows a web browser window displaying the epilepsy.com website. The address bar shows the URL: [www.epilepsy.com/get-help/managing-your-epilepsy/managing-my-seizures-101](http://www.epilepsy.com/get-help/managing-your-epilepsy/managing-my-seizures-101). The page features a navigation menu with options: LEARN, GET HELP, MAKE A DIFFERENCE, and CONNECT. The main content area is titled "Managing My Seizures 101" and includes a sidebar with a table of contents, a main article titled "Why do I need to manage my seizures?", and a social media sharing section. An advertisement for the "2015 Epilepsy Pipeline Community Conference" is visible at the top, and another advertisement for the "Epilepsy & Seizures 24/7 Helpline" is on the right side of the article.

ADVERTISMENT

**2015 Epilepsy Pipeline Community Conference**  
+ INFORMATION + EMPOWERMENT + HOPE + COMMUNITY  
Saturday, May 16, 2015, Turnberry Inn Miami, Aventura, Florida  
→ [Learn More and REGISTER TODAY!](#)

**EPILEPSY FOUNDATION**

SIGN IN FIND US IN YOUR AREA DONATE

LEARN GET HELP MAKE A DIFFERENCE CONNECT

## Managing My Seizures 101

Find Your Local Epilepsy Foundation

Managing Your Epilepsy

- Managing My Seizures 101
- Epilepsy Self Management
- My Health Care Team
- Working With Your Epilepsy Team
- Staying in Touch with Your Health Care Team
- Assessing My Readiness, Risks And Needs
- Setting Priorities And Taking Actions
- My Seizures Know More
- Understanding Seizures and Emergencies

### Why do I need to manage my seizures?

Seizures and epilepsy are chronic problems for most people. Yes, seizures can be controlled with medicines for 2 out of 3 people, but it takes work to make this happen. For people with uncontrolled seizures, it may take even more work to find other ways of managing seizures. Your health care team, and even this website will give you lots of information. Here we want you to learn what to do with the information so you can be prepared.

Based on self-management concepts, managing my seizures is designed to help people with epilepsy and their loved ones learn self-management skills and get help. This section covers key areas of epilepsy management and link you to other resources you'll find helpful.

Make sure you check the [Tool Box](#) for forms and resources to help you in your journey!

Authoried by: [Steven C. Schachter, MD](#) | [Patricia O. Shafer RN, MN](#)  
Reviewed by: [Patricia O. Shafer RN, MN](#) on 8/2013

2 0 0 2

Share Tweet +1 Like Print

ADVERTISMENT

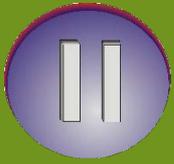
**Epilepsy & Seizures 24/7 Helpline**  
**1-800-332-1000**  
en Español 1-866-748-8008

**24/7**

Providing Help for today and Hope for tomorrow.

5:55 PM 5/7/2015





# PAUSE

To Learn About Your Epilepsy

# PERSONNEL



**Dilip K. Pandey, MD, PhD**  
Principal Investigator  
Epidemiologist



**Jeffery A. Loeb, MD, PhD**  
Co-PI  
Epileptologist



**Yevgenya Kaydanova, MD, PhD**  
Co-Investigator  
Epileptologist



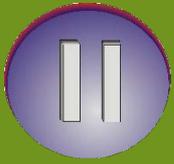
**Christina Amidei, RN, PhD, FAAN**  
Epilepsy Nurse

**Patricia O. Shafer, RN, MN**  
Consultant  
Epilepsy Foundation  
Epilepsy Nurse Specialist  
Beth Israel Deaconess Medical Center

**Möise-Denis Jean, MPH**  
Research Specialist



**Illinois Prevention  
Research Center**



**PAUSE**

To Learn About Your Epilepsy

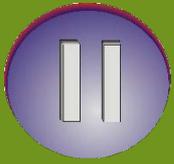
# Acknowledgments

- This work is conducted by the Illinois Prevention Research Center, funded by cooperative agreement No. U48-DP005010 from the Centers for Disease Control and Prevention, and administered by the Institute for Health Research and Policy at the University of Illinois at Chicago.



**INSTITUTE FOR  
HEALTH RESEARCH  
AND POLICY**





**PAUSE**

To Learn About Your Epilepsy

# Acknowledgments

- The content of this presentation is solely the responsibility of the authors and does not necessarily represent the official views of the Centers for Disease Control and Prevention, or the State of Illinois.
- Learn more at <http://go.uic.edu/IllinoisPRC>



**Illinois Prevention  
Research Center**