

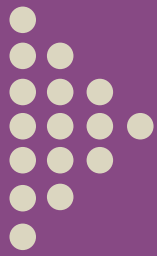


PRC

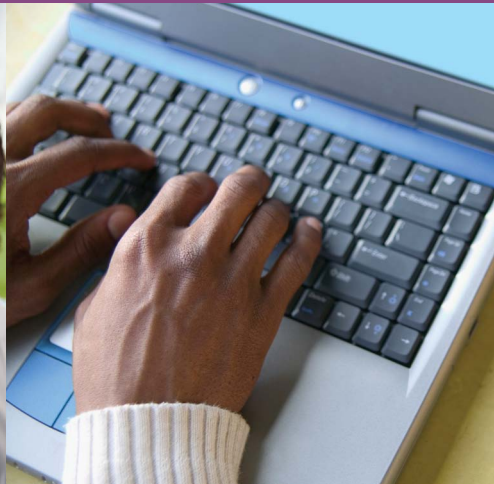
**MANAGING EPILEPSY WELL NETWORK
PUTTING COLLECTIVE WISDOM TO WORK
FOR PEOPLE WITH EPILEPSY**

National Center for Chronic Disease Prevention and Health Promotion
Division of Population Health





This booklet describes the structure and mission of the CDC Managing Epilepsy Well (MEW) Network and presents selected network accomplishments. The MEW Network is a thematic network of CDC's Prevention Research Centers (PRC) Program and is funded by CDC's Epilepsy Program.





About the Managing Epilepsy Well Network

Since 2007, the CDC Managing Epilepsy Well (MEW) Network has provided national leadership in developing, testing, and disseminating innovative self-management programs, tools, and trainings for epilepsy professionals to help people with epilepsy better manage their disorder and enhance their quality of life. National and local organizations, federal agencies, health care organizations, and people with epilepsy all participate in the network, comprising a wide range of clinical, public health, social service, and personal expertise.

This expertise has led the network to develop programs that people with epilepsy can use in their homes, at their doctor’s offices, or in other community settings. Some of these programs are made available through the telephone, personal computers, and other electronic devices to eliminate barriers to care such as lack of access to transportation, functional limitations, and stigma that many people with epilepsy face when seeking care.

Contents

Epilepsy and Epilepsy Self-Management.....	2
The MEW Network’s Community of Practice.....	3
MEW Network Member and Partner Organizations.....	4
MEW Network Workgroups	6
Epilepsy Self-Management Programs.....	7
Programs That Emphasize Both Physical Health and Mental Health	9
Selected Research Findings	12



Did you know?

• About 1 out of 26 people will be diagnosed with epilepsy during their life.

• Doctors have described more than 30 different types of seizures.

• First aid involves keeping the person safe during the seizure. Learn more at www.cdc.gov/epilepsy.



Epilepsy and Epilepsy Self-Management

Epilepsy is one of the most common neurological disorders, affecting more than 2.3 million people in the United States—including men and women, people of all ages, and all racial and ethnic groups.

• Because seizures range in severity, type, and effect and can occur alongside other conditions, epilepsy is also referred to as a spectrum disorder. All seizures involve abnormal electrical activity in the brain that causes an involuntary change in body movement or function, sensation, awareness, or behavior. Usually, a seizure lasts from a few seconds to a few minutes. Epilepsy has many causes, including brain injury, central nervous system infection, stroke, and family tendency, but in the majority of cases, the cause is unknown.

• Although there are medications to help prevent seizures, they are not always completely successful—one-third of those with epilepsy who receive treatment still experience seizures. Uncontrolled seizures can increase risk of injury, depression, anxiety, brain damage, and in rare cases, death. Uncontrolled seizures can also interfere with normal day-to-day activities such as working, going to school, and socializing with friends and family. For some people with epilepsy, treatment can be complex, and treatment side-effects (such as memory problems) can add to the challenges of living with epilepsy.

• As with any chronic condition, many people with epilepsy can benefit from learning skills and techniques that help them better manage their disorder, its treatment, and its effects to live full and satisfying lives.

Epilepsy self-management encompasses three broad areas:

Treatment management (such as adhering to medication regimens and communicating with physicians)

Seizure management (such as recognizing seizure triggers and keeping track of seizures)

Lifestyle management (such as getting adequate sleep, reducing stress, and maintaining social support networks)

• Adopting and reinforcing self-management behaviors requires an active partnership between a person with epilepsy, the person's health care provider, and family and friends. The MEW Network addresses the gap in evidence-based programs for epilepsy self-management by developing effective programs and tools to help people with epilepsy address the areas listed above.

The MEW Network's Community of Practice

The MEW Network forms a community of practice—all participants share the common concern of managing epilepsy well and work together to deepen collective knowledge and expertise by interacting on an ongoing basis. The collaborating centers are equal partners in defining the structure of the network and in setting the network's research agenda and priorities. The MEW Network website at www.sph.emory.edu/ManagingEpilepsyWell expands the network capacity and reach.

Members continuously identify and track meaningful outcomes such as products, collaboration, and network expansion to gauge the network's progress and success. In addition to these valuable outcomes of the MEW network, the network also has an effect on the field of public health by—

- Measuring progress and promoting industry standards of research in the field of epilepsy self-management

- Supporting and promoting key national initiatives

- Improving analytic and reporting capabilities

- Supporting professional training opportunities

- Sharing information about MEW Network programs with professionals and the public

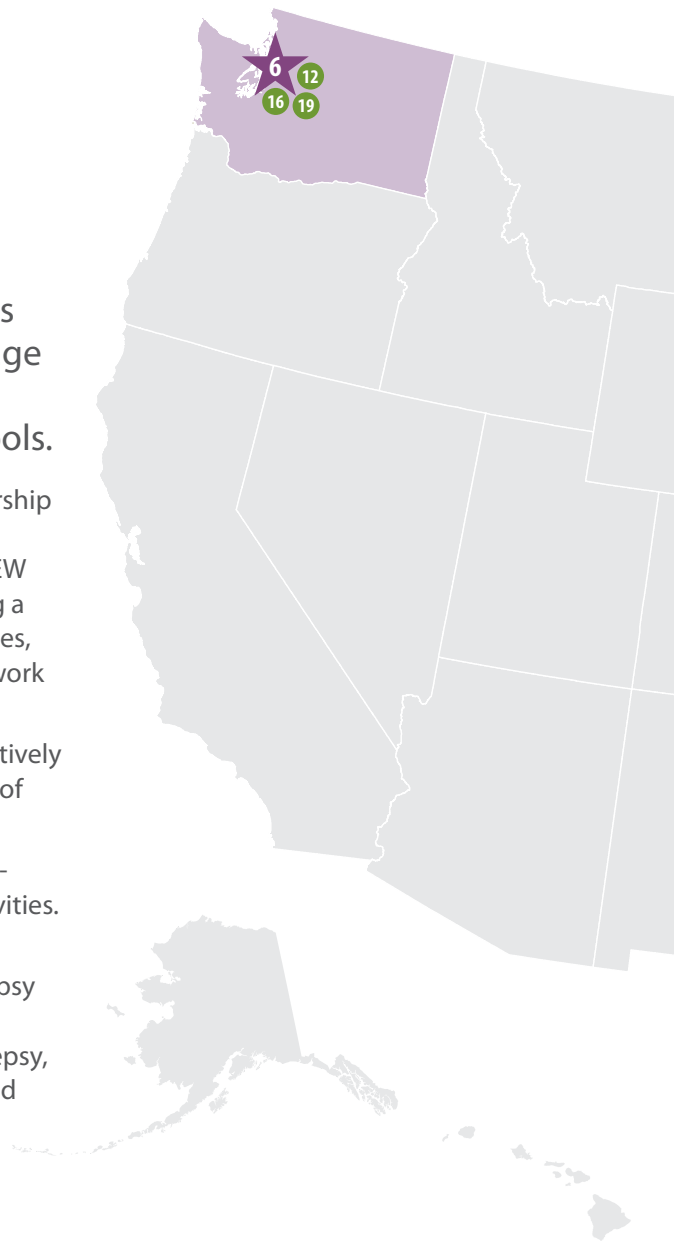




The MEW Network

The MEW Network comprises a coordinating Prevention Research Center (PRC), collaborating PRCs, institutional partners, affiliate members, and an industry partner. Together, the network is able to expand its capacity and expertise, leverage resources, and enhance the dissemination and sustainability of MEW Network programs and tools.

- The primary goal of the coordinating PRC is to provide leadership and coordination of efforts across the MEW Network. This includes coordinating a communication infrastructure for MEW Network investigators and collaborating PRCs and facilitating a multisite research agenda to guide collaboration opportunities, engage new community partners, and coordinate MEW Network dissemination and evaluation activities.
- Institutional partners are affiliated with member PRCs and actively participate in the research, development, and dissemination of self-management programs, tools, and trainings.
- Affiliate members have experience or interest in epilepsy self-management and are involved in specific MEW Network activities. They do not receive funding through the CDC PRC Program.
- The MEW Network has one industry partner—UCB, The Epilepsy Company™. It distributes biopharmaceuticals globally and actively supports educational programs for people with epilepsy, their caregivers, and the general public to raise awareness and understanding of the disorder. For more information about programs and resources that UCB supports for the epilepsy community, visit www.epilepsyadvocate.com.

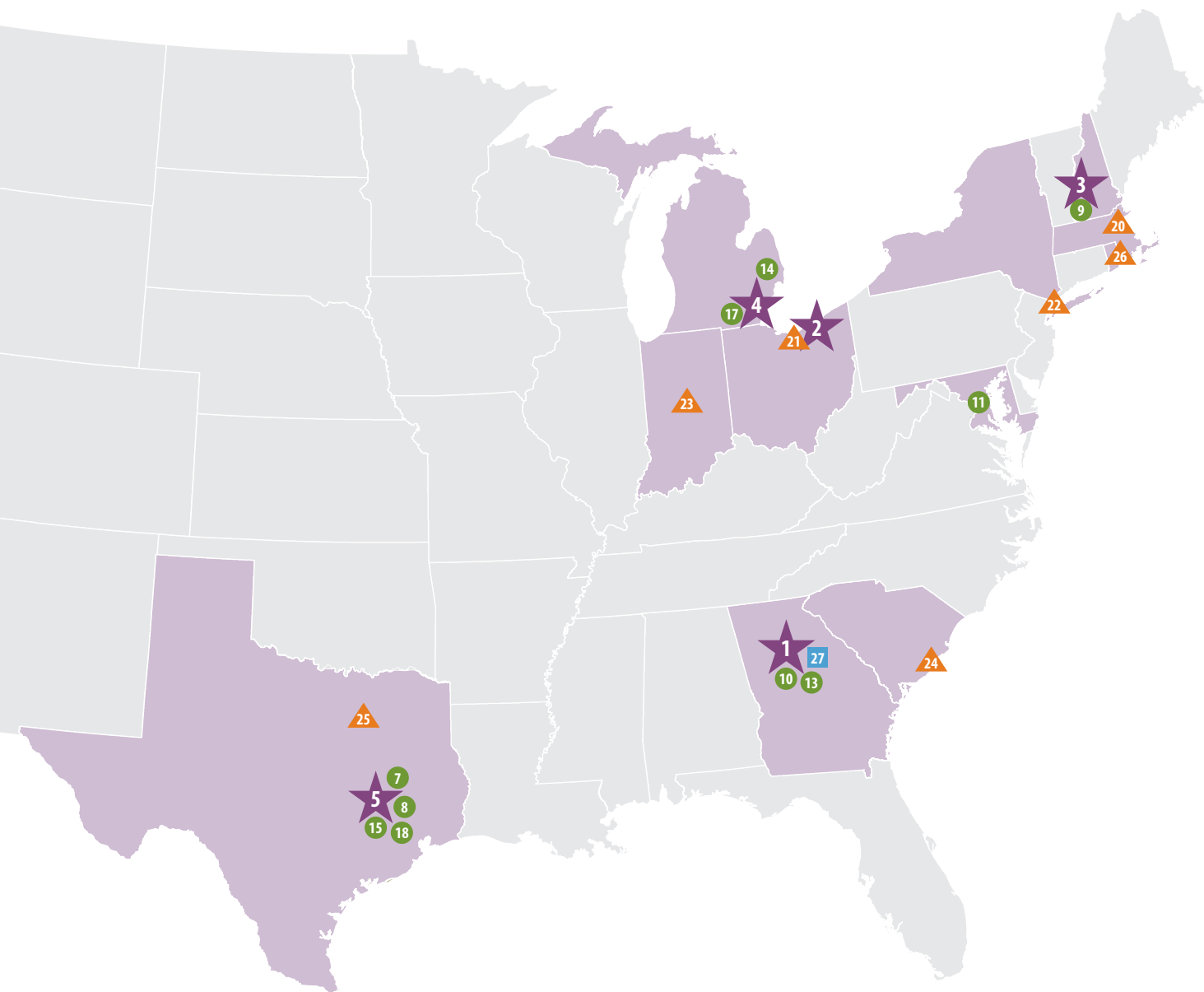


★ Prevention Research Centers

- [1] Emory University Prevention Research Center
— Coordinating Center
- [2] Case Western Reserve University Prevention Research Center
- [3] Dartmouth College Prevention Research Center
- [4] University of Michigan Prevention Research Center
- [5] University of Texas Health Science Center
at Houston Prevention Research Center
- [6] University of Washington Prevention Research Center

● Institutional Partners

- [7] Baylor College of Medicine
- [8] Ben Taub General Hospital
- [9] Dartmouth-Hitchcock Epilepsy Center
- [10] Emory University Epilepsy Clinic
- [11] Epilepsy Foundation
- [12] Epilepsy Foundation Northwest
- [13] Epilepsy Foundation of Georgia
- [14] Epilepsy Foundation of Michigan
- [15] Kelsey-Seybold Clinic



▲ Affiliate Members

■ Industry Partner

- [16] Swedish Neuroscience Institute
Epilepsy Center
- [17] University of Michigan, Department
of Neurology
- [18] University of Texas Neurology Clinic
- [19] University of Washington Department
of Rehabilitation Medicine and
Department of Neurology

- [20] Comprehensive Epilepsy Center, Beth Israel
Deaconess Medical Center
- [21] Epilepsy Association
- [22] Epilepsy Foundation of Metropolitan New York
- [23] Indiana University School of Nursing
- [24] Medical University of South Carolina,
College of Nursing
- [25] Parkland Health & Hospital System's Epilepsy
Outreach Program
- [26] Rhode Island Hospital

- [27] UCB



MEW Network Workgroups

As a community of practice, the MEW Network provides a forum for colleagues both inside and outside of the network to participate in and lead network workgroups. The purpose of a workgroup is to accelerate a project related to advancing a particular epilepsy self-management topic.

Self-Management Measurement Tool

Most MEW Network projects include self-management as the key outcome, but there is not yet a standard way to measure improvements in this area. This workgroup collaborates to define epilepsy self-management, identify its components, draft a measurement tool, obtain expert review of the tool, and conduct a series of studies to assess the reliability and validity of the tool.

eTools and Technology

This workgroup examines the use and effectiveness of electronic tools (eTools) and technology in delivering epilepsy self-management. The use of technology has the potential to increase access to self-management programs among people with limited mobility or people in rural areas. Accomplishments include the preparation and publication of an article describing the use of e-tools for chronic disease and epilepsy self-management.

Self-Management in Pediatric Epilepsy

This workgroup is identifying the main topics of epilepsy management in pediatric epilepsy and determining the challenges of transitioning from family-centered to independent epilepsy management. Members will conduct a comprehensive literature review, publish an article of current programs that are available for pediatric epilepsy, and develop research questions that address or look at self-management among young people with epilepsy and their families.

Dissemination and Sustainability

This workgroup coordinates and enhances the dissemination, implementation, and sustainability of research findings and products produced by the network. Accomplishments include coordinating a series of public webinars on epilepsy self-management and developing a social networking strategy, which includes recording podcasts and using Twitter to share information about the MEW Network programs (@MEWNetwork).

National Integrated Database

This workgroup is developing an integrated database across the six network PRCs to create a common resource for data capturing, storage, sharing, and query. The database will facilitate efficient use of resources and will enhance collaborative efforts between centers. The integrated database will also store data about non-network programs that show other successful ways to help care for people with epilepsy.





Epilepsy Self-Management Programs

The MEW Network coordinating and collaborating sites work together to develop and evaluate self-management programs. Network members share input, expertise, and resources with one another across the sites.

■ **WebEase (Epilepsy Awareness, Support, and Education)** is an Internet-based program with three self-management modules:

- Medication adherence
- Stress reduction
- Sleep management

With guidance from this program, individuals can create a personalized plan and set goals to change or maintain their self-management skills. They are also prompted to reflect on their progress, which helps reinforce desired behavior or guide new plans. In addition to the three modules, the online program includes MyLog (an epilepsy-related personal diary), additional online resources, and access to the Epilepsy Foundation eCommunities (where WebEase users can connect with others who have had personal experience with epilepsy).

With help from The Epilepsy Foundation of Georgia, Emory University recruited adults with epilepsy who participated in the initial program development and evaluation. Results from two studies showed that WebEase improved users' self-efficacy, medication adherence, perceived stress, sleep quality, and knowledge. In collaboration with the national Epilepsy Foundation, WebEase was publicly launched in June 2012, and is available online as a web-based program and is expected to be available in 2014 as a mobile application.

"The modules helped me to make plans and schedules, helping me manage my medication, stress, and sleep. The program allowed me to see how each module played a part in [better] seizure management."

—WebEase Participant



WebEase At-A-Glance

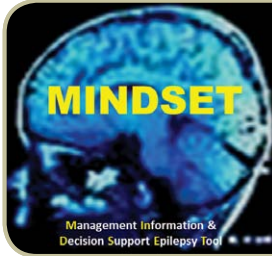
Audience: Adults with epilepsy

Distinguishing Feature: Web-based and mobile epilepsy self-management program

PRC: Emory University

More Information: www.sph.emory.edu/ManagingEpilepsyWell/WEBEASE

MINDSET (Management Information & Decision Support Epilepsy Tool) is a clinic-based computer program designed to enhance epilepsy self-management communication between patients and their health care providers. MINDSET is available on a computer tablet that is used by the patient and provider during a regular clinic visit. On the basis of the patient's symptoms, recent behavior, and their thoughts and attitudes, the program provides the patient and provider with information on the patient's self-management needs and recommendations on important discussion points regarding the patient's goals and self-management action plan. This program is currently being tested through the University of Texas Health Sciences Center at Houston.



MINDSET At-A-Glance

Audience: Adults with epilepsy and their health care providers

Distinguishing Feature: Patient-provider communication through technology

PRC: University of Texas Health Sciences Center at Houston

F.O.C.U.S. on Epilepsy is intended for adults with epilepsy and one key member of their social support network. The program emphasizes the central role of the individual and their social support in epilepsy management and is designed to help participants learn about epilepsy and daily self-management skills through

A face-to-face workshop for people with epilepsy and each of their individual supporters

A series of telephone coaching sessions for both the person with epilepsy and their support person

Informational materials

Support people learn support skills while people with epilepsy focus on a self-management area, assess their habits, set a goal, develop improvement strategies, connect their efforts to results, and build confidence. The University of Michigan partnered with the Epilepsy Foundation (EF) of Michigan and several other EF affiliates to recruit participants to test the effectiveness of this program.

- Figure** out the problem or issue
- Observe** your routine
- Choose** a goal to change
- Undertake** a strategy
- Study** the results and select a reward



F.O.C.U.S. At-A-Glance

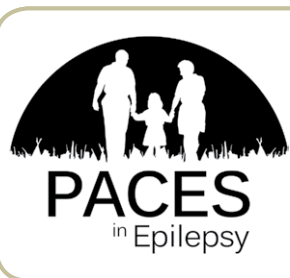
Audience: Adults with epilepsy and one key person from their support network

Distinguishing Feature: Building social support and problem-solving skills

PRC: University of Michigan

▀ **PACES for Epilepsy (Program for Active Consumer Engagement in Self-Management)** is an epilepsy self-management program that is tailored for individuals' specific self-management needs (such as stress, mood, and memory and information processing concerns). Participants learn about epilepsy and seizures, strategies for improving mood and cognitive functioning, coping skills, self-advocacy, and ways to get the most out of their health and medical care.

Information from a survey of 160 adults with epilepsy, focus groups, and consultation with partners at Epilepsy Foundation affiliates was used to develop this program. The 8-week program for urban-dwelling adults involves in-person group sessions with a trained professional, a peer leader with epilepsy, and 6–8 adults with epilepsy. The program is being adapted for people who live in more rural areas as well. The adaptation will be called PACES-R and will use distance-based phone, Internet, and peer support approaches. Both programs are coordinated by the University of Washington.



PACES At-A-Glance

Audience: Adults with epilepsy

Distinguishing Feature: Active consumer engagement in developing the program content, modified according to urban or rural location

PRC: University of Washington



Programs That Emphasize Both Physical Health and Mental Health

While epilepsy and mental illness are separate conditions, people with epilepsy often suffer from depression, anxiety, worry, negative feelings about life, and difficulties with memory and concentration. In fact, about half of people with epilepsy experience depression and anxiety. The MEW Network prioritized the mental health needs of people with epilepsy and has focused on this research area since 2009.

▀ **UPLIFT (Using Practice and Learning to Increase Favorable Thoughts)** is an 8-week program delivered through the Internet or by telephone to groups of adults who have both epilepsy and depression. Participants are taught how to identify and modify their thoughts and to become aware of and nonreactive to negative thoughts. Participants practice relaxation exercises and skills, including monitoring their thoughts, identifying problems and supports available to address them, and setting goals. Intervention groups are co-facilitated by a trained peer with epilepsy and a graduate student, both under the supervision of a licensed, clinical psychologist. Emory University studied the effectiveness of the program and found that participants' depressive symptoms decreased

“The people I met through this program helped alleviate some of the depression I was experiencing. The program widened my purpose and perspective, and taught me concrete skills to prevent depression.”

—UPLIFT Participant

significantly, and their knowledge and skills increased significantly after completing the program. With funding from the National Institutes of Health, Project UPLIFT was modified into a depression prevention intervention. The modified program proved to be effective in preventing depression among people with epilepsy through a multisite evaluation across the MEW Network. The program is being disseminated with a goal to recruit and train at least one licensed mental health professional from each of the 50 states. The training is free and offers continuing education credits.



UPLIFT At-A-Glance

Audience: Adults with both epilepsy and depression or adults with both epilepsy and depressive symptoms (in the case of depression prevention)

Distinguishing Feature: Group therapy through the Internet or by telephone

PRC: Emory University

More Information: www.sph.emory.edu/ManagingEpilepsyWell/UPLIFT

▪ **PEARLS (Program to Encourage Active, Rewarding Lives)** is an effective home-based depression treatment program for adults with epilepsy, adapted from a program developed for older adults. The program is delivered by a trained counselor in the client’s home and consists of eight 50-minute sessions. Through these one-on-one visits, the participant learns how to address issues that contribute to depression, such as social isolation and lack of physical activity. The program uses a team-based approach, involving doctors, nurses, and social workers to help the individual overcome depression. Research from the University of Washington has shown that adults with epilepsy who participate in the PEARLS program are less depressed and have fewer suicidal thoughts over 12 to 18 months than patients who receive usual care. On the basis of the proven success of the program, PEARLS’s team-based approach is recommended by *The Community Guide* for effectively managing depression.

With CDC support, PEARLS investigators developed a 2-day PEARLS training program for providers and administrators to learn how to use PEARLS methods and implement PEARLS in their communities. PEARLS training is now available through online training modules and offers professional certification credits.



PEARLS At-A-Glance

Audience: Adults with both epilepsy and depression

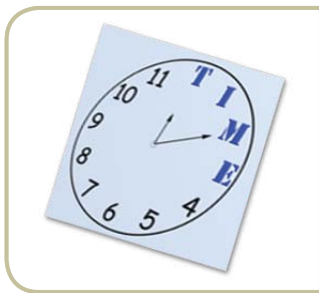
Distinguishing Feature: Home-based program that features coordination between different care providers

PRC: University of Washington

More Information: www.pearlsprogram.org

▀ **TIME (Targeted Self-Management for Epilepsy and Mental Illness)** is intended for adults with both epilepsy and a serious mental illness (SMI) such as severe depression, bipolar disorder, or schizophrenia. Researchers from Case Western Reserve University are adapting a self-management program originally shown to be effective among adults with diabetes and SMI.

The TIME program consists of 12 weekly group sessions that include education, behavioral modeling, and group support. A key feature of TIME is that groups are co-led by a nurse educator and a peer educator. During these sessions, the group addresses the challenges that a person is likely to experience when they have both epilepsy and a serious mental illness. Educational topics include personalized goal setting, medication adherence, and dealing with the double stigma of having both epilepsy and SMI. Once the TIME program is fully developed and if it improves the symptoms of both epilepsy and SMI, it is intended for use by a variety of community and health care settings.



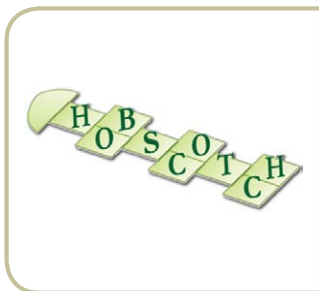
TIME At-A-Glance

Audience: People with both epilepsy and a serious mental illness

Distinguishing Feature: 12-week group sessions with a nurse educator and a peer educator

PRC: Case Western Reserve University

▀ **HOBSCOTCH (HOMe-Based Self-management and COgnitive Training CHanges Lives)** is a program designed to address memory and attention problems among people with epilepsy through a combination of in-person visits, telephone calls, and a gaming device. Approximately half of people who experience seizures report more difficulties with memory than people without seizures. Reasons for memory loss may include medications, stress, brain structure, brain chemistry, and brain activity. Through HOBSCOTCH, each participant selects one specific memory problem per week and uses a strategy to cope with the problem. The gaming device is designed to be a fun, inexpensive way to improve memory for adults with epilepsy and does not require Internet access. The program is currently being tested for effectiveness, which will include measures of quality of life, memory perceptions, and memory function. Researchers will also determine if the program increases knowledge and skills related to epilepsy self-management.



HOBSCOTCH At-A-Glance

Audience: People with both epilepsy and difficulties with memory

Distinguishing Feature: Telephone and home-based program supported by use of hand-held gaming device

PRC: Dartmouth College



Selected Research Findings

The MEW Network members are committed to disseminating research findings and assuring that effective programs and resources are available to people with epilepsy. Network information is shared in a variety of formats for a variety of audiences.

- In May 2012, MEW Network members conducted the first in a series of webinars dedicated to the topic of self-management. The intent of the series was to provide an overview on how self-management differs from patient education programs, and to highlight MEW resources. These webinars are intended for a wide range of community epilepsy stakeholders and are publicly available on the MEW website at www.sph.emory.edu/ManagingEpilepsyWell. Also available on the website are podcast interviews with researchers from each of the network centers highlighting various programs and studies.
- The MEW Network shares its findings in the scientific peer reviewed and professional literature, on its website, and at professional conferences and events. The following are some publication highlights from the network:

Begley CE, Shegog R, Iyagba B, et al. Socioeconomic status and self-management in epilepsy: comparison of diverse clinical populations in Houston, Texas. *Epilepsy Behav.* 2010;19(3):232-238.

Chaytor N, Ciechanowski P, Miller JW, et al. Long-term outcomes from the PEARLS randomized trial for the treatment of depression in patients with epilepsy. *Epilepsy Behav.* 2011;20(3):545-549.

Clark NM, Stoll S, Sweetman M, Youatt EJ, Derry R, Gorelick A. Fostering epilepsy self management: the perspectives of professionals. *Epilepsy Behav.* 2010;19(3):255-263.

Dilorio C, Bamps Y, Walker ER, Escoffery C. Results of a research study evaluating WebEase, an online epilepsy self-management program. *Epilepsy Behav.* 2011;22(3):469-474.

Dilorio C, Bamps Y, Edwards AL, et al. The prevention research centers' managing epilepsy well network. *Epilepsy Behav.* 2010;19(3):218-224.

Escoffery C, Dilorio C, Yeager KA, et al. Use of computers and the Internet for health information by patients with epilepsy. *Epilepsy Behav.* 2008;12(1):109-114.

Fraser RT, Johnson EK, Miller JW, et al. Managing epilepsy well: self-management needs assessment. *Epilepsy Behav.* 2011;20(2):291-298.

Fraser RT, Miller JW, Johnson EK. Epilepsy. In: Flanagan S, Zaretsky HH, Moroz A, eds. *Medical Aspects of Disability, Fourth Edition: A Handbook for the Rehabilitation Professional*. New York: Springer; 2010. p. 177-194.

Shegog R, Bamps Y, Escoffery C, et al. Managing epilepsy well: emerging etools for epilepsy self-management. *Epilepsy Behav.* 2013;29(1):133-140.

Thompson NJ, Walker ER, Obolensky N, et al. Distance delivery of mindfulness-based cognitive therapy for depression: Project UPLIFT. *Epilepsy Behav.* 2010;19(3):247-254.

Walker ER, Obolensky N, Dini S, Thompson NJ. Formative and process evaluations of a CBT and mindfulness intervention for people with epilepsy and depression. *Epilepsy Behav.* 2010;19(3):239-246.

Did you know?

Between 2007 and 2013, the MEW Network has been responsible for more than

• Thirty scientific journal articles.

• Two book chapters.

• Twenty-nine scientific presentations and posters.



To learn more about how PRCs help their communities, contact the Centers for Disease Control and Prevention National Center for Chronic Disease Prevention and Health Promotion.

www.cdc.gov/prc



Healthier Communities Together

For the most up-to-date information on what the MEW Network is doing to promote epilepsy self-management, see www.cdc.gov/epilepsy and www.sph.emory.edu/ManagingEpilepsyWell.

For information about the Prevention Research Centers, see the program's website at www.cdc.gov/prc, or please contact:

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion
4770 Buford Highway NE, Mail Stop F-78, Atlanta, GA, 30341-3717
E-mail: cdcinfo@cdc.gov | 770-488-5395