



At-a-Glance 2016



The Centers for Disease Control and Prevention (CDC) supports the Managing Epilepsy Well (MEW) Network, whose mission is to advance the science related to epilepsy self-management by facilitating and implementing research, conducting research in collaboration with network and community stakeholders, and broadly disseminating the findings.

EVIDENCE-BASED PROGRAMS:

- **HOBSCOTCH** (Home Based Self-management and Cognitive Training Changes Lives): Dissemination of a promising community-based self-management program for people with epilepsy and cognitive dysfunction (Caller et al., *Epilepsy Behav*, 2015, in press)



- **PACES** (Program for Active Consumer Engagement in Epilepsy Self-Management): Adaptation of the PACES program for phone-delivery to veterans and adults with epilepsy (Fraser et al. *Epilepsia*, 2015, 56 (8), 1264-74)



- **PEARLS** (Program to Encourage Active Rewarding Lives): A home-based, collaborative-care depression treatment intervention for people with epilepsy (Ciechanowski, et al., *Epilepsy Behav*, 2010 19(3):225-231; Chaytor et al., *Epilepsy Behav*, 2011, 20(3):545-549)



- **Project UPLIFT** (Using Practice and Learning to Increase Favorable Thoughts) for Epilepsy: An Internet and telephone intervention using cognitive behavioral therapy and mindfulness to treat and to prevent depression in people with epilepsy (Thompson et al., *Epilepsy Behav*, 2010, 19(3):247-254; Thompson et al, *J Consult Clin Psych*, 2015, 83(2), 304-313.)



- **WebEase** (Web Epilepsy Awareness Support and Education): An Internet self-management program to improve medication adherence, stress and sleep management (DiIorio et al., *Health Ed Res*, 2009, 24(2), 185-197; DiIorio et al., *Epilepsy Behav*, 2011, 22(3): 469-474). Available at www.webease.org



PROGRAMS UNDER EVALUATION:

- **MINDSET** (Management Information & Decision Support Epilepsy Tool): Evaluation of a decision-support software for the clinical management of epilepsy among Hispanic-American Adults (Shegog et al. *Epilepsy Behav*, 2013, 29(3), 527-36; Begley et al. *Epilepsy Behav*, 2015 44, 143-50)



- **SELF-MANAGEMENT TOOLS FOR AFRICAN-AMERICANS**: Community-based adaptation, evaluation, and dissemination of self-management tools among African-American adults living with epilepsy in Georgia.

- **PAUSE to Learn Your Epilepsy** (Personalized Internet Assisted Underserved Self-Management of Epilepsy): Development and evaluation of an on-line and video-conference self-management program for adults with epilepsy



- **SMART**: An on-line program to improve self-management and quality of life for adults with epilepsy and recent negative health events



- **TIME**: A person-centered, holistic program for people with epilepsy and with severe and persistent mental illness

- **Project UPLIFT** (Using Practice and Learning to Increase Favorable Thoughts): Adaptation and evaluation of UPLIFT for Hispanic-Americans with Epilepsy

- **Youth, Epilepsy and Successful Self-Management**: Development of an on-line program for youth with epilepsy



Follow us on Twitter @MEWNetwork



On-line: managingepilepsywell.org

SELECT STUDIES AND PUBLICATION LIST:

- DiIorio et al. (2010). “The Prevention Research Centers' Managing Epilepsy Well Network”. *Epilepsy Behav*, 19(3): 218-224.
- Preventing Depression in People with Epilepsy: An Extension of Project UPLIFT (Funded through the National Center for Minority Health and Health Disparities, NIH Challenge Grant Award) (*Thompson et al, J Consult Clin Psych, 2015, 83(2), 304-313.*)
- Contributing to Managing Epilepsy Well: A comprehensive review of the experiences and effects of self-management interventions for epilepsy (*Clark, et al., Epilepsy Behav, 2010, 19(3), 255-63*)
- Developing Community-Based Self-Management Programs for Adults with Epilepsy (*Fraser R et al., Epilepsy Behav, 20(2), 291-98*)
 - Up-to-date list of 40+ peer-reviewed publications and 7 book chapters for MEW research studies available at: <http://goo.gl/XOP5Zd>

TOOLS AND TRAINING:

- University of Michigan’s Center for Managing Chronic Disease Key Informants’ Perspectives on Managing Epilepsy Report: <http://goo.gl/ysd1rC>
- PEARLS Training: Seattle WA (offered yearly since 2009): www.pearlsprogram.org/
- Adult Epilepsy Self-Management Measurement Instrument (AESMMI) (*Escoffery et al., Epilepsy Behav, 2015, 50, 172–83 and 184–89*)
- UPLIFT Training for Mental Health Professionals (available after January 2013): Contact Nancy Thompson (nthomps@emory.edu) for additional information
- Webinar Series on Epilepsy Self-Management: <http://goo.gl/T8VM9i>

COMMUNITY OF PRACTICE WORKGROUPS:

- *Managing Epilepsy Well Article* (2015-present): Provide an updated overview of MEW Network activities since 2010
- *Self-Management in Pediatric Epilepsy* (2013-present): Identify the domains of epilepsy management in pediatric epilepsy
- *Self-Management Measurement Tool Workgroup* (2010-2015): Develop a common measure of epilepsy self-management for research and clinical use (*Escoffery et al., Epilepsy Behav, 2015, 50, 172–83 and 184–89*)
- *Ontology-driven MEW Data Portal* (2013-2014): identify and implement the preliminary steps towards an integrated database for the MEW Network
- *Dissemination and Sustainability* (2011-2014): Coordinate and enhance the dissemination, implementation and sustainability of MEW research and programs
- *eTools and Technology* (2011-2012): Examine the use and the impact of eTools and technology on epilepsy self-management (*Shegoy et al., Epilepsy Behav, 2013, 29(1):133–140*)

On-line <http://managingepilepsywell.org/>

Contact information:

Barbara Jobst, MD, Dr. med, FAAN, Dartmouth-Hitchcock, Principal Investigator, Barbara.C.Jobst@Hitchcock.org

Nancy J. Thompson, PhD, MPH, Emory University, Co- Investigator: nthomps@emory.edu

Rosemarie Kobau, MPH, MAPP, CDC Epilepsy Program: rmk4@cdc.gov



Follow us on Twitter @MEWNetwork



On-line: managingepilepsywell.org