Results

Self-Management Programs

- **WebEase (Web Epilepsy Awareness, Support and Education):** An Internet self-management program to improve medication adherence, stress management, and sleep (Dilorio C et al., 2009).

- **Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts):** An Internet and telephone intervention using cognitive behavioral therapy and mindfulness to treat depression in people with epilepsy (Thompson NJ et al., 2010).

- **PEARLS (Program to Encourage Active Rewarding Lives):** A home-based, collaborative care depression treatment intervention modified for people with epilepsy (Ciechanowski et al., 2010; Chaytor et al., 2011).

Completed Research Studies

- **Contribute to Managing Epilepsy Well:** A thorough review of the literature and existing programs to identify chronic disease and epilepsy self-management models, and key informant interviews with epilepsy health and social service providers to examine perceived unmet needs regarding self-management (Clark NN et al., 2010).

- **Socioeconomic differences in epilepsy self-management and its impact on treatment adherence, healthcare use, and health outcomes:** An examination of the relative importance of attitudinal, social, behavioral, and environmental antecedents in predicting self-management behavior and the relative importance of self-management behavior in predicting treatment adherence and outcomes by socioeconomic status (Rigby CE et al., 2010).

- **Developing community-based self-management programs for adults with epilepsy:** An assessment of the medical and psychosocial concerns of adults with epilepsy relative to the development of a self-management program intervention (Frazier et al., 2011).

Tools & Training

- **Key Informants' Perspectives on Managing Epilepsy Report:** Self-management needs-assessment report based on the findings of key informant interviews with epilepsy health and social service providers (University of Michigan's Center for Managing Chronic Disease, 2010).

- **PEARLS Training:** A CDC-supported community-based depression treatment intervention for adults with epilepsy, Seattle, WA (offered yearly since 2009).

Research in Progress

- **Focus on Epilepsy:** Development and pilot-testing of a self-management intervention combining skill building for self-regulation for adults with refractory epilepsy and training for significant individuals providing social support to those with epilepsy.

- **Consume-generated epilepsy self-management intervention:** Development and pilot-testing of an intervention for adults with epilepsy with a continuing emphasis on cognitive compensatory strategies and emotional coping as a complement to all the educational modules.

- **MINDSET (Management Information & Decision Support Epilepsy Tool):** Development and pilot-testing of a clinic-based decision-support system to enhance self-management behavior. This software program will be mounted on a Personal Digital Assistant (PDA) and will assist patients and their health care providers in communicating about the patient’s epilepsy self-management and to more effectively enhance this behavior.

- **Measurement tool for epilepsy self-management:** Development of a standard measurement tool of epilepsy self-management behaviors for use by researchers, clinicians and people with epilepsy.

Multi-Site Research

- **Preventing Depression in People with Epilepsy: An Extension of Project UPLIFT:** Revision of Project UPLIFT materials so that they can be used for prevention (and not treatment) of depression, and assessment of the effectiveness of the revised materials in reducing the risk of depression in people with epilepsy and mild to moderate depressive symptoms, as well as increasing their knowledge and skills for preventing depression and improving their quality of life. This study is funded through the National Center for Minority Health and Health Disparities, NIH Challenge Grant Award.

Website

www.sph.emory.edu/ManagingEpilepsyWell/ (Figure 1)

Figure 1: www.sph.emory.edu/ManagingEpilepsyWell/

Conclusions

The MEW Network provides an important forum for the study of epilepsy self-management and for the dissemination of epilepsy self-management programs.

MEW Network sites are:

- Contributing to a fuller understanding of self-management in epilepsy
- Examining contextual variables that may influence the successful implementation of self-management programs
- Informing the epilepsy community about self-management needs and opportunities
- Using e-health tools to extend the reach of epilepsy self-management programs to the broad population of people with epilepsy
- Crafting targeted self-management programs for subgroups of people with epilepsy

References

- PEARLS (Program to Encourage Active Rewarding Lives). Available at: http://www.pearlss.org/.