ICARE Member Report:  
**CDC-supported Research on Comorbidities of Epilepsy**

- **Comorbid conditions of interest**
  - Any separate health condition *associated* with epilepsy, especially:
    - Autism
    - Developmental disabilities
    - Other neurologic disorders complicated by epilepsy
    - Depression and anxiety disorders
CDC Epilepsy Comorbidity Research: Aims and Methods

• Research questions
  ▫ Public health ‘burden’:
    • Incidence and prevalence
    • Impact, e.g., disability, quality of life
  ▫ Risk factors and predictors of outcome
    • Opportunities for prevention
  ▫ Interventions to reduce occurrence or impact
    • E.g., self management

• Tools of research
  ▫ Population-based surveys
  ▫ Epidemiologic studies of populations
    • Cross-sectional or cohort
  ▫ Other comparative cohort studies
Research on Public Health Burden, Risk Factors, and Predictors of Outcome

Surveillance and Epidemiologic Studies
“Risk Factors of Epilepsy Outcomes: Comorbidities in Populations with Epilepsy”

- **Principal Investigator:** Anbesaw Selassie, DrPH, Medical University of South Carolina, Charleston, SC
- **Focus/relevance:** Prevalence of common comorbid conditions among people with epilepsy (PWI); relation of comorbidities and epilepsy outcomes; healthcare utilization and cost
- **Methods:** Retrospective cohort of cases of epilepsy from linked statewide datasets (hospital inpatient, outpatient, office, Medicare, Medicaid), as well as abstracted medical records.
- **Duration:** Up to 5 years, commenced September 2011
“Epidemiologic Research and Surveillance in Pediatric Epilepsy”

- **Principal Investigator:** Barbara L. Kroner, PhD, RTI International, Rockville, MD
- **Focus/relevance:** Incidence and prevalence of epilepsy and comorbidities in children; healthcare utilization, barriers to care; risk factors, and outcomes.
- **Methods:** Cohort of 500 children from the two principal pediatric medical centers in Washington DC, followed for two years. Data from administrative sources, medical records reviews, and parent questionnaires.
- **Duration:** Up to 5 years, commencing September 2011
• “Prevalence of Epilepsy and Comorbidities in the U.S. Adult Population”
  ▫ Principal Investigator: Rosemarie Kobau, MPH, Centers for Disease Control, Atlanta, GA
  ▫ Focus/relevance: Prevalence of epilepsy and common comorbidities in the U.S. adult population
  ▫ Methods: Cross-sectional study of epilepsy prevalence, AED use, seizure frequency, access to specialty care, and associated health conditions, using data from the 2010 National Health Interview Survey.
  ▫ Duration: Periodic—biennial or triennial
“Autism and Developmental Disabilities Monitoring (ADDM) Network”

- Principal Investigator: Marshalyn Yeargin-Allsop, MD, Centers for Disease Control & Prevention, Atlanta, GA
- Focus/relevance: Prevalence of autism spectrum disorders (ASD), developmental disabilities, and epilepsy in U.S. children
- Methods: Serial cross-sectional study of prevalence of ASD and comorbidities—including epilepsy—among children aged 4 and 8 years, conducted in 12 communities, based on reviews of health and education records.
- Duration: Ongoing
Research on Interventions to Reduce Occurrence or Impact

Managing Epilepsy Well Network

Cohort Studies
The Managing Epilepsy Well (MEW) Network

- Mission: to advance and disseminate the science of epilepsy self-management through research conducted in collaboration with network and community stakeholders.
- Four collaborating centers:
  - Emory Univ., Atlanta
  - Univ. of Texas, Houston
  - Univ. of Michigan, Ann Arbor
  - Univ. of Washington, Seattle

http://www.sph.emory.edu/ManagingEpilepsyWell/
Selected MEW Network Programs

- **WebEase (Web Epilepsy Awareness Support and Education)**

- **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

- **PEARLS (Program to Encourage Active Rewarding Lives)**
  - A home-based depression treatment intervention for adults with epilepsy and co-morbid depression
  - Chronic care model
  - 8 fifty-minute sessions over 19 weeks then by 5-10 min. by phone
  - Components: Problem-solving treatment; pleasant events scheduling; social & physical activation; psychiatric supervision (Ciechanowski et al. Epilepsy & Behavior 2010; 19:225-231)

**RCT, n=148**

![Graph showing changes in Medication Adherence Score over Baseline, Interim, and Posttest periods for Treatment and Waitlist groups.](image-url)
UPLIFT is Effective in Reducing Depression

- RCT, n=40
- ↓ depressive sx and ↑ knowledge & skills to reduce depression
  - Significant improvement compared to controls
    - Both phone & web interventions
  - Major and minor depressive disorders
  - Effect sustained
PEARLS Improves Depression & Quality of Life

- RCT, n=80
- Significant ↓ depressive sx
- Effect sustained


Fig. 3. Change in QOLIE-31 total score and subscale scores from baseline to 12 months (positive change reflects improved quality of life).
Next Steps.....

WebEase
• Launched via EF web site June, 2012
• Smartphone app in development

UPLIFT
• Emory funding for UPLIFT in cystic fibrosis
• UPLIFT CEU training modules in development
• Need implementation sites

PEARLS
• In-person training (Sept. 28, 2012, Seattle, WA)
• On-line training modules in development
• Need implementation sites