

ICARE Member Report

- **CDC Epilepsy Program**
National Center for Chronic Disease Prevention and Health Promotion
Centers for Disease Control
- **Mission**
To address public health issues related to epilepsy:
 - to improve the health of people living with epilepsy, and
 - to improve their quality of life

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- Major topics of interest in epilepsy research
 - Population surveillance:
 - addresses prevalence, seizure frequency, access to specialty care, comorbidity, quality of life
 - Population-based epidemiologic studies of epilepsy
 - Focus on incidence, prevalence, health disparities, distribution by type and severity, patterns of health care
 - Prevention Research (self-management; depression treatment & prevention)
 - Research to promote epilepsy self-management programs and to improve the quality of life for people with epilepsy, e.g., addressing medication adherence, , sleep, social support, communication with health care providers, depression and anxiety reduction,
 - In collaboration with CDC's Prevention Research Centers' Managing Epilepsy Well (MEW) Network.

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- Types of research support or other activities
 - **Surveillance:**
 - Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Interview Survey (NHIS)
 - See Kobau R et al. Epilepsy Surveillance Among Adults — 19 States, Behavioral Risk Factor Surveillance System, 2005. *MMWR Morbidity and Mortality Weekly Report* 2008; 57 (SS-6):1-24.
 - **Epidemiologic studies**
 - Multiple localities include AZ, DC, KS, NM, NY, SC, TX
 - See handout.
 - **Self management**
 - The Managing Epilepsy Well (MEW) Network
 - 4 collaborating centers – Emory University, University of Texas at Houston, University of Michigan, and University of Washington
 - Effective interventions demonstrated for improving self-management (internet-based) and for depression prevention programs (community-based and internet- and telephone-based)
 - See DiIorio CK et al. The prevention research centers' Managing Epilepsy Well Network. *Epilepsy & Behavior* 2010; 19(3):218-24.

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Highlighted example – CDC-supported surveillance

BRFSS findings on access to specialty care:

[Kobau R et al. *MMWR* 2008; 57(SS-6).]

- 44% of people with epilepsy report recent seizures—nearly one-third more than expected
- Of those having recent seizures, one third have not seen a neurologist or epileptologist in the past year
- We need additional population-based epidemiologic research on:
 - Barriers to receiving care
 - Barriers to successful treatment
 - Strategies for improvement

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Highlighted example – CDC-supported epidemiologic research:

A population-based study of risk of epilepsy after hospitalization for traumatic brain injury

- Ferguson PL et al. *Epilepsia*, 51(5):891–898, 2010
- **Purpose:** to determine risk of posttraumatic epilepsy (PTE) in persons hospitalized with traumatic brain injury (TBI).
- **Methods:**
 - Stratified random sample of persons with TBI aged ≥ 15 years, identified in SC hospital discharge dataset, 1999-2002
 - Medical records reviewed; up to 3 yearly follow-up telephone interviews.

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▫ Ferguson PL et al. *Epilepsia*, 51(5):891–898, 2010

- **Results:**

- Cohort size 2,118 persons

- 3-year Cumulative incidence of PTE:

- Mild 4.4%

- Moderate 7.6%

- Severe 13.6%

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- **Opportunities for collaboration**
 - CDC emphasizes *population-based* epidemiologic research & surveillance.
 - Defines true public health burden of conditions
 - Identifies populations at high risk
 - Ensures representativeness (and generalizability) of findings
 - Complements clinical research conducted by NIH and other agencies
 - Helps to inform health care policy & research
 - Focus of CDC population research can be directed to needs of other agencies
 - Opportunities for direct collaboration with NINDS
 - (See following slides)

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- **Priorities and/or plans for future activities**
 - Continue CDC support for population-based epidemiologic studies of epilepsy in representative localities
 - Develop CDC/NINDS collaboration in support population surveillance of SUDEP and other epilepsy-related mortality
 - Explore CDC/NINDS population-based incident epilepsy cohort / registry for epidemiologic and clinical study.

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Addendum

- For exploration: A CDC-NINDS collaboration for ongoing population-based incident cohort studies (or incident case registries)
 - Support epidemiologic research on incidence, comorbidities, patterns of care, early predictors of outcomes, other determinants of outcomes.
 - Could serve as a representative source population for clinical research (NINDS)
 - Some could be focused on population strata at increased risk (e.g., children)