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


**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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Highlighted example – CDC-supported epidemiologic research:

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


**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)