ICARE Member Report

- CDC Epilepsy Program

  National Center for Chronic Disease Prevention and Health Promotion

  Centers for Disease Control and Prevention

- Mission Description

  To promote:

  - knowledge of the epidemiology, public health burden, and impacts of epilepsy; and
  - prevention of epilepsy and its adverse consequences through
    - reduction of risk factors for epilepsy and its comorbidities
    - developing and disseminating interventions that improve quality of life for people with epilepsy and
    - working with partners to change systems and environments to better support people with epilepsy.

ICARE Member Report: CDC Epilepsy Program

- Major topics of interest in epilepsy research
  - Population surveillance:
    - addresses prevalence, comorbidities, quality of life
  - Population-based epidemiologic studies of epilepsy
    - Focus on incidence, prevalence, distribution by type and severity, health disparities
  - Prevention Research
    - Primary prevention (e.g., TBI, stroke, CNS infection prevention)
    - Secondary prevention (e.g., access to appropriate care, improved self-management, reduction of comorbidities)

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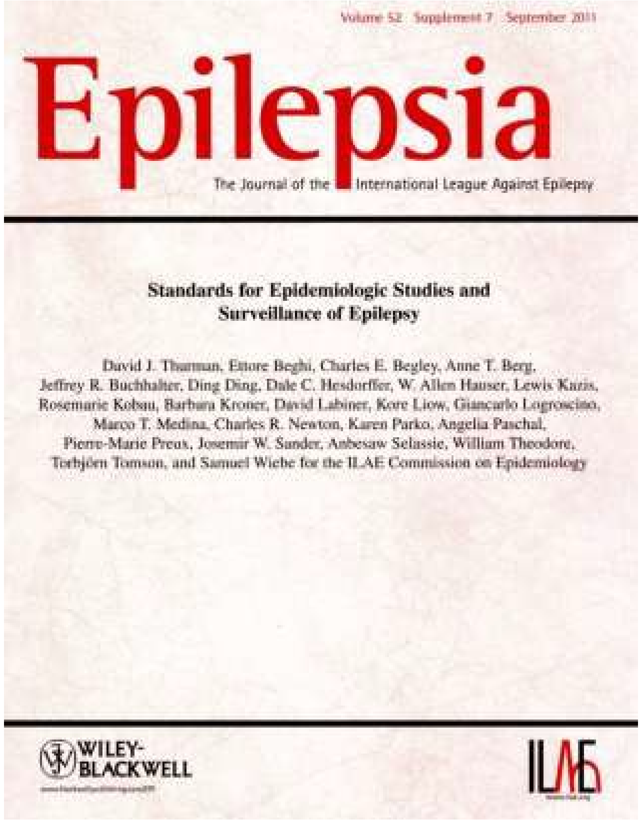
CDC Epilepsy Program

- Types of research support or other activities
  - Surveillance:
    - National Health Interview Survey (NHIS) – biennial or triennial survey on epilepsy;
    - Tracks progress on *Healthy People 2020* objective to improve access to care for people with epilepsy.
  - Epidemiologic studies
    - Multiple localities include **AZ**, **DC**, KS, NM, **NY**, **SC**, TX
    - CDC / ILAE Standardized methodologies
  - Self management
    - The Managing Epilepsy Well (MEW) Network
      - 4 collaborating university centers



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Epilepsia

The Journal of the International League Against Epilepsy

Standards for Epidemiologic Studies and
Surveillance of Epilepsy

David J. Thurman, Ettore Beghi, Charles E. Begley, Anne T. Berg,
Jeffrey R. Buchhalter, Ding Ding, Dale C. Hesdorffer, W. Allen Hauser, Lewis Kazis,
Rosemarie Kobau, Barbara Kroner, David Labiner, Kore Liow, Giancarlo Logroscino,
Marco T. Medina, Charles R. Newton, Karen Parko, Angelia Paschal,
Pierre-Marie Preux, Josemir W. Sander, Anbesaw Selassie, William Theodore,
Torbjörn Tomson, and Samuel Wiebe for the ILAE Commission on Epidemiology

WILEY-BLACKWELL

ILAE

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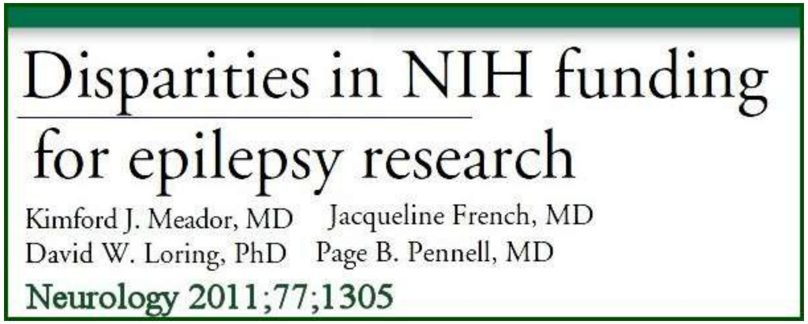
CDC Epilepsy Program

- Opportunities for collaboration
  - CDC emphasizes epidemiologic research & surveillance and complements basic and clinical research.
    - Defining true public health burden useful in setting research priorities
    - Helps to inform health care policy



Disparities in NIH funding for epilepsy research

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Neurology 2011;77;1305

  - Subjects of CDC-supported incident cohort studies (or an incident cohort registry) could form a representative population for some clinical studies
  - Epilepsy mortality surveillance system(s) could provide representative sources for tissue banks for SUDEP research.

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- Priorities and/or plans for future activities
  - Continue CDC support for epidemiologic studies of epilepsy in representative localities
    - Incident cohort studies
    - Focus on comorbidities, populations at high risk, disparities, early predictors of outcome
  - Continue CDC support for self-management research
  - Develop CDC/NINDS/NHLBI collaboration for population surveillance of SUDEP and other epilepsy-related mortality