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.
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• 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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• 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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• 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
  ▫ 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.

Disparities in NIH funding for epilepsy research
Kimford J. Meador, MD  Jacqueline French, MD
David W. Loring, PhD  Page B. Pennell, MD
Neurology 2011;77;1305
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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