

ICARE Member Reports

Epilepsy Program Centers for Disease Control and Prevention

National Center for Chronic Disease Prevention
and Health Promotion

www.cdc.gov/epilepsy

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- Mission : to effectively address public health issues related to epilepsy in order to
 - 1) improve the health of people living with epilepsy, especially those at greater risk for health disparities;
 - 2) improve their quality of life; and
 - 3) decrease the stigma associated with this condition.



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Major topics of interest in CDC epilepsy research

- Public health surveillance and population-based epidemiologic studies:
 - to define the *incidence* and *prevalence* in representative communities;
 - to define *risk factors* and *severity*;
 - to identify *health disparities* and their contributing factors; and
 - to describe *outcomes* of epilepsy, including factors such as type of epilepsy, socioeconomic status, access to and quality of health care;
- Improving and validating *methods* for conducting epidemiologic studies
- Identifying measures that define *optimum care*.

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- *Epidemiologic Research, 2003-2010*
 - Northern Manhattan: incidence and prevalence
 - South Carolina: prevalence and incidence
 - Navajo Nation: prevalence
 - Southern Arizona: prevalence
 - Houston and New York City: socioeconomic determinants of outcomes
 - South Carolina: socioeconomic determinants of outcomes
 - United States: epilepsy prevalence & treatment patterns in older adults; incidence and comorbidities in nursing home residents
 - Southeastern Kansas: prevalence and comorbidities in children
 - Harlem, New York City: predictors of outcome in a follow-up study of incident cases

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- *Surveillance*

- Behavioral Risk Factor Surveillance System (BRFSS)
 - Prevalence
 - Access to specialty care
 - Activity limitations and health-related quality of life
- National Health Interview Survey (NHIS)
 - Prevalence
 - Access to specialty care
 - Activity limitations and comorbidities
- Link to new Healthy People 2020 Objective
 - “Increase the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care.”

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- ***Primary Prevention Research***

- Development of serologic screening methods for taeniasis and neurocysticercosis (with CDC National Center for Emerging and Zoonotic Infectious Diseases)
- Other primary prevention programs under purview of other CDC programs, e.g., injury prevention, cardiovascular disease prevention.

- ***Secondary Prevention Research***

- Managing Epilepsy Well (MEW) Network
 - Four university centers
 - Focus on home- and community-base interventions to improve epilepsy self management and prevent depression

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Resources and other opportunities for collaboration

- CDC epidemiologic research is complementary to NINDS basic and clinical research
- CDC research on access to care and optimal care relates closely to interests of AHRQ and HRSA
- CDC supports advocacy organization work (Epilepsy Foundation) to provide public and patient education, information to enhance self-management, and programs to reduce stigma

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Priorities for future research

- National Health Interview Survey
 - Access to appropriate care, comorbidities, and quality of life
- Population-based epidemiologic studies
 - Incidence and prevalence in diverse U.S. populations
 - Early predictors of epilepsy outcomes
 - Comorbidities
 - Emphasis on age groups of highest incidence (children, older adults)



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Priorities for future research (cont.)

- Fully defining the public health burden of epilepsy through population-based studies
 - Updated cost estimates
 - Disability and quality of life
 - Health disparities
- Epilepsy mortality surveillance
 - Including SUDEP and injury-related mortality