

# LIVING \*WITH EPILEPSY

TASK FORCE UPDATE  
A BLUEPRINT FOR THE FUTURE



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American Epilepsy Society  
The Centers for Disease Control and Prevention  
Epilepsy Foundation  
Health Resources and Services Administration  
National Institute of Neurological Disorders and Stroke

This publication was supported by a grant from the Centers for Disease Control and Prevention (CDC 5U58DP00606-03). Its contents are solely the responsibility of the Epilepsy Foundation and do not necessarily reflect the official views of the CDC, the Department of Health and Human Services, or the federal government.

# Living with Epilepsy A Blueprint for the Future

The Living with Epilepsy Task Force was established following the release of the Living Well with Epilepsy II Conference Report in 2005. Member organizations include the American Epilepsy Society (AES), the American Academy of Neurology (AAN), the Epilepsy Foundation, the Centers for Disease Control and Prevention (CDC), the National Association of Epilepsy Centers (NAEC), the Health Resources and Services Administration, (HRSA), and the National Institute of Neurological Disorders and Stroke (NINDS).

The charge of the task force is to oversee the implementation of the conference recommendations cited in the conference proceedings report, and expand each organization's efforts to continue to move forward our mutual agenda to improve the lives of people affected by epilepsy through research, education, empowerment and public awareness. Examples of activities of the partners since the conference which continue today include improving health care access for families through the development of access to care systems which increase the timeliness of treatment; increasing availability of specialty services and the development of treatment guidelines to benchmark quality care; and educating consumer and health care providers about epilepsy's consequences, especially in the areas of mental health and cognition.

# Living with Epilepsy — A Blueprint for the Future

## Goals and Objectives for 2009-2012

Furthermore, the partners are committed to establishing models of care that foster empowerment and independence for people with epilepsy and developing surveillance systems to address the burden of disease and co-morbid conditions, syndromes of early childhood, mortality risks and more precise estimates of prevalence. Our work includes a national education effort to reduce the stigma associated with the condition, and new research and health communications strategies designed to combat stigma that are both age and culturally appropriate. Finally, the partners recognize how critical public education is to improving seizure recognition and first aid.

Significant progress has been made in addressing the recommendations from the Living Well with Epilepsy II conference by these organizations, as well as others in the epilepsy community. None the less, there is still much to do moving forward. In developing the attached “**Blueprint for the Future**” for people living with epilepsy, the member organizations remain cognizant of the continued challenges faced by families across the nation living with this condition and are committed to continued outreach to offer professional and public education for health care providers and family caregivers.

### Goal A: Improve Access to Care for Families Living with Epilepsy

#### Objective:

- *Advocate for improved patient care and treatment by increasing the number and availability of specialists in the field.*

Lead Agencies: American Academy of Neurology  
Health Resources and Services Administration  
Epilepsy Foundation

#### Objective:

- *Improve patient care through the establishment of epilepsy practice treatment guidelines.*

Lead Agencies: American Academy of Neurology  
Health Resources and Services Administration  
Epilepsy Foundation  
National Association of Epilepsy Centers

#### Objective:

- *Support efforts to create electronic medical information systems that protect the individual's privacy, allow for individual access, and promote the portability of records and information.*

Lead Agencies: American Academy of Neurology  
Health Resources and Services Administration  
Epilepsy Foundation

#### Objective:

- *Promote policies that protect access to all FDA approved treatment options.*

Lead Agencies: American Academy of Neurology  
Epilepsy Foundation  
American Epilepsy Society  
National Association of Epilepsy Centers

**Objective:**

- *Encourage the federal agencies that oversee access to medication and treatment for epilepsy to research and analyze the issue of equivalence among different manufacturers' versions of the same therapeutic product, and to ensure such medications are safely interchangeable for the individual with chronic seizures.*

Lead Agencies: American Academy of Neurology å  
Epilepsy Foundation  
American Epilepsy Society å  
National Association of Epilepsy Centers å

**Objective:**

- *Support efforts to implement a national network of VA Epilepsy Centers of Excellence to provide needed diagnosis, treatment, education and research for service-related epilepsy as a consequence of traumatic brain injury as established in the VA Epilepsy Centers of Excellence Act of 2007.*

Lead Agencies: American Academy of Neurology å  
Epilepsy Foundation  
American Epilepsy Society å

**Objective:**

- *Establish a system to measure the impact of surgical intervention on health outcomes, as well as develop quality criteria for surgical centers.*

Lead Agencies: American Academy of Neurology å  
National Association of Epilepsy Centers å

**Objective:**

- *Support a randomized trial of 'customary care' versus early referral to specialized care.*

Lead Agencies: National Institute of Neurological Disorders and Strokes  
National Association of Epilepsy Centers  
Epilepsy Foundation

**Objective: å**

- *Develop consensus criteria on the warning signs of seizures and epilepsy. å*

Lead Agencies: American Academy of Neurology å  
American Epilepsy Society å  
Epilepsy Foundation å

**Objective:**

- *Support access for children with epilepsy and seizures to full inclusion in all community based services and educational activities whether or not they need such auxiliary services such as access to medication and treatment in order to safely participate in such educational activities.*

Lead Agencies: Epilepsy Foundation  
Health Resources and Services Administration

**Objective:**

- *Support training and/or issuance of guidance or rules for first responder agencies that would result in adoption of universal protocols and training requirements for first responders.*

Lead Agencies: American Academy of Neurology å  
Epilepsy Foundation å  
Centers for Disease Control and Prevention å

## **Goal B: Increase Epilepsy Research**

**Objective:**

- *Support research that prevents epilepsy and its progression by identifying unrecognized causes, identifying biological mechanisms and biomarkers that contribute to the development of seizures.*

Lead Agency: National Institute of Neurological Disorders and Stroke

**Objective:**

- *Expand epilepsy research to include psychosocial, mental health, behavioral, and cost studies including nursing and educational approaches.*

Lead Agencies: National Institute of Neurological Disorders and Stroke  
Epilepsy Foundation  
Centers for Disease Control and Prevention

**Objective:**

- *Support research that focuses on vulnerable populations with epilepsy including women, aging and other underserved populations.*

Lead Agencies: National Institute of Neurological Disorders and Stroke  
Epilepsy Foundation  
Centers for Disease Control and Prevention

**Objective:**

- *Encourage the use of brain bank resources to facilitate the study of death in epilepsy.*

Lead Agencies: Epilepsy Foundation  
American Academy of Neurology

**Objective:**

- *Support research within federal agencies such as Department of Defense and Veterans Affairs on epilepsy and seizures as a result of traumatic brain injury including the VA Epilepsy Centers of Excellence.*

Lead Agencies: Epilepsy Foundation  
American Academy of Neurology

**Objective:**

- *Conduct and support research projects that focus on the epidemiology of epilepsy, including incidence and prevalence, risk factors, co-morbidities, and health disparities.*

Lead Agencies: Centers for Disease Control and Prevention  
Epilepsy Foundation

**Objective:**

- *Include questions related to epilepsy on national and state health surveys.*

Lead Agencies: Centers for Disease Control and Prevention  
Epilepsy Foundation

**Objective:**

- *Develop new treatment strategies and improve current approaches in order to cure epilepsy.*

Lead Agencies: National Institute of Neurological Disorders and Stroke  
Epilepsy Foundation  
American Epilepsy Society

**Objective:**

- *Support government policies that ensure the adequate protection of people in clinical trials and work to require that all clinical trials be posted on [www.clinicaltrials.gov](http://www.clinicaltrials.gov), including those with outcomes that may be adverse.*

Lead Agencies: National Institute of Neurological Disorders and Stroke  
American Academy of Neurology  
Epilepsy Foundation  
American Epilepsy Society

## **Goal C: Increase Awareness, Education and Research Regarding SUDEP**

**Objective:**

- *Develop educational materials and programs on risk of death in epilepsy and its prevention for professional and lay audiences.*

Lead Agencies: American Epilepsy Society  
Epilepsy Foundation  
Centers for Disease Control and Prevention

**Objective:**

- *Secure infrastructure grants, develop uniform criteria, and facilitate the research activities of a consortium of centers to conduct clinical and basic science studies to identify preventable risk factors and determination of SUDEP.*

Lead Agencies: American Epilepsy Society  
Epilepsy Foundation  
National Institute of Neurological Disorders and Stroke

**Objective:**

- ***Convene a multidisciplinary workshop to refine currently identified lines of investigation and to identify additional areas of research into mechanisms underlying SUDEP.***

Lead Agencies:  American Epilepsy Society  
National Institute of Neurological Disorders and Stroke  
Epilepsy Foundation  
American Academy of Neurology

**Objective:**

- ***Create a database or registry of autopsy findings to facilitate the evaluation of death in epilepsy.***

Lead Agencies: National Institute of Neurological Disorders and Stroke  
American Epilepsy Society  
Centers for Disease Control and Prevention

## **Goal D: Remove All Barriers to Education, Community, and Workplace Opportunities for Children, Youth, and Adults Living with Epilepsy**

**Objective:**

- ***Support expansion of programs affecting people with epilepsy, including those authorized by the following laws: the Workforce Investment Act Amendments of 1998; the Social Security Act; the Development Disabilities Act; the Lifespan Respite Care Act; and the Children’s Health Act of 2000.***

Lead Agency:  Epilepsy Foundation

**Objective:**

- ***Support programs that educate employers and vocational rehabilitation specialists about epilepsy, educate people with epilepsy regarding their rights, and assist young people with epilepsy as they move into the workforce.***

Lead Agencies:  Epilepsy Foundation  Centers for Disease Control and Prevention 

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