

Project Access Newsletter

About Project Access

Project Access is a national effort designed to improve access to comprehensive, coordinated health care and related services for children and youth with epilepsy. The project consists of active participation on the part of state agencies, physicians and other health care providers, families, schools, and community resources to implement demonstration projects in states to improve access to health services and to achieve early detection and treatment for children and youth with epilepsy and seizure disorders.

* This program was made possible by funding from the Maternal Child Health Bureau of the Health Resources Services Administration

Current News and Articles

Key Informants' Perspectives on Managing Epilepsy

The Center for Managing Chronic Disease has released a report entitled *Key Informants' Perspectives on Managing Epilepsy*. The report paints a vivid picture of the challenges and opportunities in the area of epilepsy management based on key themes that emerged from 101 key informant interviews with professionals who work to improve the lives of those with epilepsy: clinicians, social service providers, researchers, and others.

Article in The Huffington Post: Help Us Bring Epilepsy Out of the Shadows

This article by Lynda Resnick describes a recent brainstorming session which involved the American Epilepsy Society, The Epilepsy Foundation, the Epilepsy Therapy Development Project, the International League Against Epilepsy and Citizens United for Research on Epilepsy to develop a unified message around epilepsy.

New Study: Self-Esteem and Symptoms of Depression in Children with Seizures

A new study titled *Self-esteem and symptoms of depression in children with seizures: Relationships with neuropsychological functioning and family variables over time* sought to test over time the relationships of neuropsychological functioning to mental health in children following a first recognized seizure, and to determine if the strength of these relationships differ based on risk and protective factors. The study found that seizure onset had a negative impact on mental health in children with declines in cognitive functioning except for older children and those with more family resources.

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Electrical System of the Brain

Resources and Tools

Cultural and Linguistic Competence Family Organization Assessment Instrument

The National Center for Cultural Competence at Georgetown University Center for Child and Human Development has created an organizational self-assessment instrument to address the unique functions of family organizations concerned with children and youth with behavioral-emotional disorders, special health care needs, and disabilities.



Sustainability Toolkit: 10 Steps to Maintaining Your Community Improvements

The Center for Civic Partnerships has developed a toolkit designed to sustain the improvement you have made in your community's

health and/or quality of life. The toolkit contains:

- Examples and stories from communities throughout the nation
- Activities you can complete, which are included on a CD-Rom
- Sample plans, timeline, and completed activities
- Tips and resources

The toolkit costs \$90 and includes shipping and handling.

Funding Resources

Funding is a critical component to sustainability. We have developed a page on our Web site where you can find funding resources and opportunities, including Federal Government, private foundations, and rural health.

Here are some grant writing trainings and resources for you to utilize:

Grant Writing USA

Grant Writing USA delivers training programs across America that dramatically enhance performance in the areas of grant writing, grants management and grant maker research.

The Grantsmanship Center

Provides trainings, workshops and other resources to assist you with your grant seeking and proposal writing efforts.

Foundation Center- Online Training Courses

Provides online trainings and free

For funding resources, please visit the Project Access Web site at http://www.epilepsyfoundation.org/projectaccess/Resources/funding_resources.cfm

tutorials to help you navigate the philanthropic community.

U.S. Government Grants: Grant Writing Workshops, Courses, and Trainings

U.S. Government Grants (USGG) is a national grant writing training and consulting company offering a full range of services to a diverse group of educational institutions, government agencies, nonprofit organizations and professional grant writers throughout the United States and Puerto Rico.

For funding resources, please visit the [Project Access Web site](#).

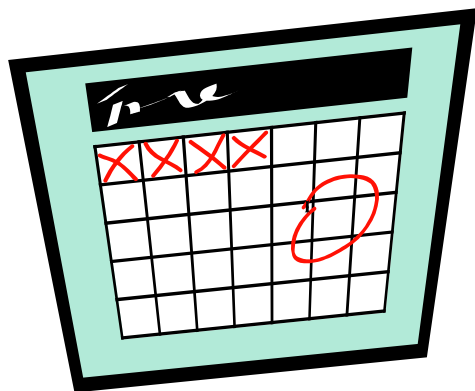
Innovative Strategies for Serving Children and Youth with Epilepsy (Project Access)

Due Date: June 21, 2010

The purpose of this program is to support innovative strategies in improving access to care for children and youth with epilepsy. Please see the link for more details.



Calendar of Events



NCPA Staff

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NCPA Grantees

Phase 1 (2004-2007):

CA- Children's Hospital of Los Angeles
IL- Epilepsy Foundation of Greater Chicago
MS- Epilepsy Foundation of Mississippi
NJ- Epilepsy Foundation of New Jersey
OR- Easter Seals Oregon
Washington D.C.- D.C. Department of Health
WV- Center of Excellence in Disabilities at WV University
WI- Medical College of Wisconsin

Phase II (2007-2010):

CA, AK, NY, WY- Children's Hospital of Los Angeles, EF of Northern CA, EF Northwest, EF Colorado
ME, NH- Trustees of Dartmouth College, EF of MA and RI
WA- WA State Dept of Health, EF Northwest
FL, NY- Epilepsy Foundation, EF of FL, EF or Metropolitan NY

[Centers for Disease Control and Prevention \(CDC\) National Conference on Health Communication, Marketing, and Media](#)
August 17-19, 2010
Atlanta, GA

[Association of University Centers on Disabilities \(AUCD\)](#)
Crystal City, VA
October 31-November 3, 2010

[American Public Health Association \(APHA\) Denver, CO](#)
November 6-10, 2010

[Centers for Disease Control and Prevention \(CDC\) National Conference on Health Communication, Marketing, and Media](#)
August 17-19, 2010
Atlanta, GA

[National Rural Health Association \(NRHA\) Multiracial and Multicultural Conference](#)
December 1-3, 2010
Tucson, AZ

[American Epilepsy Society \(AES\)](#)
San Antonio, TX
December 3-7, 2010

Epilepsy Foundation

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The Epilepsy Foundation is the national voluntary agency dedicated solely to the welfare of the almost 3 million people with epilepsy in the U.S. and their families. The organization works to ensure that people with seizures are able to participate in all life experiences; to improve how people with epilepsy are perceived, accepted and valued in society; and to promote research for a cure. In addition to programs conducted at the national level, people with epilepsy throughout the United States are served by more than 50 Epilepsy Foundation affiliates around the country.

We are a non-profit, charitable agency, designated as a 501 (c) 3 organization by the Internal Revenue Service. Donations to the Foundation and its affiliates are tax deductible as allowed by law.

Grantee Products and Tools

Dartmouth-Hitchcock Children's Hospital at Dartmouth

Podcasts and videos: Experts from Dartmouth-Hitchcock Medical Center and Project Access offer advice and information for parents and medical professionals about the intricacies of epilepsy and caring for a child with a seizure disorder. New topics are posted regularly.

Medical ID Card

The Epilepsy Foundation in Florida developed a wallet-sized card designed to be carried by the child in his or her school back pack or wallet as a handy and reliable medical summary for school or emergency situations. The Medical ID card is a safe and reliable back up for reducing potential allergic reactions/interactions, intolerances or side effect profiles.

Bi-lingual Health Care Transition Plan

The Epilepsy Foundation in metropolitan New York developed a bi-lingual health care transition plan for youth ages 17 and over.

On the Epilepsy Foundation in metropolitan New York web site,

you can also find other helpful bilingual resources, such as a Seizure Action Plan, Epilepsy Care Plan, Medication List, along with educational materials in English, Spanish, and Chinese.

For more products and resources from grantees, including evaluation tools, policy briefs, care plans, media and others, please visit the [Project Access Web Site](#).

If you are interested in providing resources for the quarterly Project Access newsletter, please email Beth Topf at btopf@efa.org.

