

From: [National Center for Project Access](#)
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Subject: Project Access Newsletter
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Project Access Newsletter December 2010	
<p>In This Issue</p> <p>Recent News and Announcements</p> <p>Phase III Grantees</p> <p>Grantee Highlight</p> <p>Resources Highlight</p> <p>Sustainability and Funding</p>	<p>This newsletter provides information, tools and resources to Project Access grantees. This newsletter is also useful to anyone interested in increasing awareness and improving access to care for children and youth with epilepsy.</p> <hr/> <p>Recent News and Announcements </p> <hr/> <p>Web Site Resources and Tools</p> <p>This is a reminder to please check out the Project Access web site located at www.accessforepilepsy.org for resources and tools, along with information about upcoming events and quick links. We are currently in the process of revamping the site to make it more user friendly and esthetically pleasing.</p> <p>We are also looking for a couple of volunteers to provide us with feedback during the revamping process. If you are interested in participating in this focus group, please contact Beth Topf at btopf@efa.org.</p> <p style="text-align: right;">NCPA Map</p> <hr/> <p>Phase III Grantees </p> <hr/> <p>Congratulations to the Innovative Strategies and Promising Practices Grantees 2010-2013! Each grantee is implementing a unique strategy to address awareness and access to care for children and youth with epilepsy. Each grantee's strategy is listed below.</p> <p>Michigan Department of Community Health Assure the best quality of health services are made available to children</p>
<p>Upcoming Events</p> <p>Project Access Grantee Meeting: February 28-March 1 Washington D.C.</p> <p>Project Access Grantee Call January 11, 2010 11:00 am-12:00pm EST</p> <p>Calendar </p>	
<p>Contact Us!</p> <p>Staff</p> <p>Deborah McGruder Project Director</p> <p>Beth Topf</p>	

Program Manager
[Valerie Hill](#)
Program Manager

About Project Access

Project Access is a national initiative funded by the [Maternal and Child Health Bureau](#) of the [Health Resources and Services Administration](#) to improve access to coordinated, comprehensive care for children and youth with epilepsy in medically underserved and rural areas. The National Center for Project Access administered by the Epilepsy Foundation serves as a clearinghouse for information, products and tools, data collection and program evaluation for professionals and the general public.

Quick Links

Websites:

www.accessforepilepsy.org
www.epilepsyandmychild.org



**Epilepsy Foundation
National Center for
Project Access**
8301 Professional Place, East
Landover, MD 20785
(301) 459-3700

and youth with epilepsy in medically underserved and rural areas using telehealth and demonstrating the increased application of medical home care coordination.

Epilepsy Foundation Western/Central Pennsylvania

Create a system of care that will result in replicable co-management practice guidelines and a new process of identifying early cognitive effects of seizures and antiepileptic medication.

Cleveland Clinic

Improve access to mental health care for youth with epilepsy- Project (COPE) Collaboration for Outreach and Prevention Education for Children/Adolescents with epilepsy.

University of Nebraska Medical Center Munroe-Meyer Institute

Improve access to specialized epilepsy services while expanding use of telehealth technologies to improve health care in rural, underserved areas.

Epilepsy Foundation of Florida, Inc.

Expand services developed in Phase II throughout Florida ensuring all children and their families have access to comprehensive services, particularly those in rural and medically underserved areas.

Epilepsy Foundation- National Office

Partner with the National Association of Community Health Centers to train care coordinators in community health centers in the states of Alabama, Louisiana, Georgia, North Carolina, and Texas,

New Hampshire Department of Health and Human Services

Integrate into the current system of care a focus on creating an alliance between coordination of care efforts including family/youth involvement in health care design statewide.

Cleveland Clinic Logo

Grantee Highlight



Project (Cope)

Collaboration for Outreach and Prevention Education for Children/Adolescents with Epilepsy

Tatiana Falcone, MD

Cleveland Clinic Epilepsy Center

What is the main goal of your project?

To improve access to mental health care for children and adolescents with epilepsy by developing a community-based, interagency, culturally and linguistically competent mental health care outreach model. To reach this goal, it is very important to educate stakeholders (providers and patients) about psychiatric co-morbidities in youth with epilepsy. During the period of this grant, we will also develop a mental health tool kit with 13 different resources that might be helpful for providers and families of children with epilepsy.

What partnerships do you have and/or are you seeking to

develop?

We will be partnering with NAMI of Greater Cleveland (The National Association for the Mentally Ill), the Cleveland Metropolitan School District and the Epilepsy Association of Cleveland.

In your opinion, what makes your project unique?

We are empowering the patients and families with knowledge about the mental health issues in patients with epilepsy, and how to advocate for the needs of the child with the providers, school and society in general. This is a community project with a core education piece. Project COPE (Collaboration for Outreach and Prevention Education for Children and Adolescents with epilepsy). Project COPE will be a series of educational talks (workshops) for children and families with epilepsy and also there will be some workshops for the classroom where the child with epilepsy is attending. Another part of Project COPE is an anti-bullying workshop and we will be delivering those at the schools for classmates and teachers. We want to educate the whole community that surrounds the youth with epilepsy, to improve knowledge about epilepsy and decrease stigma.

What do you think your biggest challenge is?

Stigma about epilepsy, stigma about mental illness, despite increased resources to target mental health problems in children with epilepsy. Sometimes the families elect not to access the services because of the stigma generated by both disorders. Empowering the families with knowledge, we will be fighting STIGMA. The more parents and the community know about some of the mental health issues and other medical issues patients with epilepsy face, the easier it will be for them to ask for help when they need it.

California Policy Brief

Resources Highlight

[California Policy Brief](#)



Project Access grantees in California developed a policy brief that provides data on the challenges facing families of children with epilepsy living in rural communities. The Policy Brief addresses: disparities between children with epilepsy and all children with special health care needs; family needs; health insurance coverage for children with epilepsy; rural health care access challenge; epilepsy-related hospitalizations; mental health; and early diagnosis and treatment.

[New York Care Book- English/Spanish](#)

The documents in this Care Book are in both English and Spanish. Parents can use these forms for meetings with their medical team or school staff. The forms included are: Seizure Action Plan; Health Care Plan; Medication List; First Aid for Seizures Card; School Seizure Log Form; Notes; Medical Appointment Log; Community Resources Guide; and Specialist & Pediatrician Communication Log.

[Epilepsy Foundation's Legal Rights of Children with Epilepsy in School and Child Care: An Advocate's Manual](#)

This manual is designed to provide detailed practical guidance to help parents/guardians and other non-attorney advocates understand the rights of children with epilepsy to school and child care services-- and to effectively advocate to secure those rights. This manual provides tools to help families advocate on their own and reach a voluntary resolution of most disputes regarding their children's rights.

Money

Sustainability and Funding

It's never too early to start thinking about your sustainability plan. The Center for Civic Partnerships provides 10 steps to maintain your community improvements.



- Step 1 - Create a Shared Understanding of Sustainability
- Step 2 - Position Your Effort to Increase Your Sustainability Odds
- Step 3 - Create a Plan to Work through the Process
- Step 4 - Look at the Current Picture and Pending Items
- Step 5 - Develop Criteria to Help Determine What to Continue
- Step 6 - Decide What to Continue and Prioritize
- Step 7 - Create Options for Maintaining Your Priority Efforts (including funding issues)
- Step 8 - Develop a Sustainability Plan
- Step 9 - Implement Your Sustainability Plan
- Step 10 - Evaluate Your Outcomes and Revise as Needed

For more information, please visit:

http://civicpartnerships.org/docs/publications/sustainability_toolkit.htm.

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