Epilepsy Awareness Month

NOVEMBER

Continue AWARENESS into 2015!
Be sure to check out all of the professional resources available on www.aap.org/epilepsy

Primary care health professionals and medical home teams must know, or have access to, current knowledge about epilepsy, including seizure recognition and diagnosis, prevention strategies and treatment options, co-morbidities, necessary psychosocial services, and the need to counter stigma. The specific educational needs are significant: making the accurate diagnosis; recognizing when referrals to subspecialists are necessary; understanding medication therapies and side effects; and ensuring care coordination and co-management with the specialists. The Academy offers a variety of resources that address caring for a child with epilepsy:

AAP TEXTBOOK OF PEDIATRIC CARE
Seizure Disorders (Point-of-Care)
Status Epilepticus
Sleep Disturbances
Prenatal Drug Abuse and Neonatal Drug Withdrawal Syndrome
Head Injuries (Point-of-Care)

PATIENT HANDOUTS
Seizures and Epilepsy

FORMS & TOOLS
Psychiatric Co-morbidities in Epilepsy - A Guide to Side Effects of Psychiatric Medications

RED BOOK ONLINE
Immunization in Special Clinical Circumstances: Children with a Personal or Family History of Seizures
The Epilepsy Foundation Western/Central Pennsylvania (EFWCP) teaches thousands of people about epilepsy and seizures each year. As grant recipients of the HRSA Epilepsy Program, the EFWCP is aiming to expand their capacity for outreach across the 49 counties in their service region by conducting a train-the-trainer program to middle school-aged children. This program will be piloted by three presenters (two EFWCP staff members and one parent volunteer) who will use a modified version of the National Centers for Disease Control and Prevention “Take Charge of the Storm” curriculum, which aims to increase awareness among middle school students and encourages the inclusion of epilepsy education in school health and science classes. The new program titled 1 in 26 (based on the statistic that 1 in 26 Americans will develop epilepsy in their lifetime) was created with input from a focus group composed of middle school-aged students, some of whom have epilepsy. The revised curriculum includes a series of videos that feature children with epilepsy talking about how it has impacted their life, provides giveaways to encourage participation, and incorporates an audience response, “clicker system,” which provides each student with a remote that allows them to interact with the presenter. The presenter can participants questions (multiple choice, yes/no, true/false, ranking), poll participants, calculate pre/post test results, and more.

To launch Epilepsy Awareness month this past November, it seemed fitting that the AAP Coordinating Center on Epilepsy spent the first few days of the month at the Project ECHO Institute® in New Mexico. One of the goals of the Center is to expand the Children and Youth with Epilepsy (CYE) teleECHO clinics into several additional states using the Project ECHO model.

Nearly 20 Pediatric Neurologists, Epileptologists, Pediatricians, Mental Health Professionals, Nurse Practitioners, and Program Staff from Missouri, Kansas, Colorado, New York, and Illinois participated in the 3 day immersion training with the Coordinating Center staff. This group learned how to use the Project ECHO methodology to build capacity among primary care providers within their states so that CYE can be seen within their medical home. These teams are now recruiting primary care providers, school nurses, and other professionals within their states to participate in the bi-weekly CYE TeleECHO clinics, which are scheduled to launch in early 2015.

Between the MCHB grantees and the Project ECHO Expansion project, the Coordinating Center is now serving 13 states! For more information, please contact Trisha Calabrese, MPH.
The First Convening of the Global ECHO Community

With 39 ECHO® hubs operating in 22 states and in 6 countries, Project ECHO is changing the way health care is delivered around the world. This year marked the very first MetaECHO conference, in which all of Project ECHO® replication partners gathered in Albuquerque, NM to share successes, ideas, and discuss how to maximize the impact of the ECHO model to reach 1 billion lives by 2025. View the conference here.

Ramesh Sachdeva, MD, PhD, JD, FAAP, AAP Associate Executive Director and Coordinating Center Principal Investigator, along with, Daniel Johnson MD, FAAP, Director of ECHO-Chicago at the University of Chicago and ECHO Expansion Project grantee, were among those invited to present at the conference.

Become inspired and view their presentations below.

Assembling of the Grantees, MCHB, and AAP Center Staff - Washington, DC

In September, the Maternal and Child Health Bureau (MCHB), the seven state grantees, and the AAP Coordinating Center, gathered for the first time to share program successes, lessons learned, and ensure that Children and Youth with Epilepsy (CYE) have access to the medical, social, and other supports and services they need. Although grantee sites vary in their specific project activities, all sites are working toward the same outcomes.

Guest presenters from Got Transition and Health Resources and Services Administration (HRSA) along with the enthusiasm and positive spirit of all the attendees helped make this meeting a success. Learn more about the seven state grantees and their projects here.
AAP Coordinating Center, in Collaboration with National Partners, is Aiming for and Accomplishing Target Goals

leading efforts to implement a community-based system of services for CYE;
supporting, enhancing, and promoting opportunities for professional, parent, and youth education, dialogue, and networking;
developing state-of-the-art quality improvement (QI) strategies with a mobilized community of learners to further support the development, implementation, evaluation, and spread of evidence-based epilepsy-related services;
improving access of CYE to quality health care and other services; and
developing and implementing a comprehensive evaluation methodology to support and monitor outcomes of the Coordinating Center and epilepsy program grantees

Visiting Professorship Program

The SONu is collaborating with the Coordinating Center on Epilepsy to develop its first visiting professorship program designed specifically to build awareness of pediatric epilepsy among residency programs. This program will offer two institutions, that don’t currently have access to epilepsy care, the opportunity to host an expert in pediatric epilepsy for two days of grand rounds, lectures, and seminars.

The intent of the visiting professorship is to bring a pediatric neurology expert to a pediatric residency program via an application process to educate the primary care clinicians and others at the state level on the issues and needs related to children and youth with epilepsy (CYE). Interested institutions that possess a pediatric residency program and demonstrate needs regarding pediatric epilepsy (e.g., those institutions in rural and/or medically underserved areas or which have limited access to an epileptologist or pediatric epilepsy expert) are encouraged to apply.

The application can be found here and are due Monday, February 2, 2015.

Applications will be reviewed by the SONu Executive Committee.

Online Application Form

Speaker List

If you have questions or would like to request additional applications, please contact Lynn Colegrove, Manager, Section on Neurology, at 800/433-9016, ext.7820 or via e-mail at: lcolegrove@aap.org.

CATCH Grant Applications Now Being Accepted

Grants of up to $10,000 for pediatricians and fellowship trainees and $2,000 for pediatric residents are available from the Community Access to Child Health (CATCH) program for innovative initiatives that ensure all children, especially underserved children, have medical homes and access to health services not otherwise available in their communities. Applications will be accepted for Planning, Implementation, and Resident Grants until January 30, 2015. For more information contact kkocvara@aap.org.
Recently, a series of five parent focus groups were held to gain insights on their understanding of motor delay and educational needs regarding child growth and development. Literature indicates that overall progress has been made in communicating with families about these issues and that parental concerns and observations are being integrated into the developmental surveillance process conducted by pediatric clinicians.

During these focus groups, parents were asked about their experiences with developmental surveillance (motor development) and screening (motor delays). Participants revealed the following:

- They lack information available to them regarding motor development in children.
- They rely heavily on other family members and their own research for information on the signs of typical or atypical motor development in children.
- They felt that initial concerns about their child’s development were often disregarded by pediatricians and they would have liked their pediatrician to be more responsive to their concerns.

“In our case, the pediatrician would say, ‘let’s wait until the next visit.’ So you end up losing time and having negative consequences…” -Anonymous focus group participant.

Access the clinical report clinical report Motor Delays: Early Identification and Management (Pediatrics, June 2013) here.

Fostering Partnership and Teamwork in the Pediatric Medical Home: A “How To” Video Series

Three instructional videos from the National Center for Medical Home Implementation show pediatric practices how to implement team huddles, family advisory groups, and care partnership support. Access the videos through the National Center for Medical Home Implementation Web site.

NEW Web Page: AAP Medical Home Resources

A new web page is now available which offers a variety of AAP medical home resources specific to AAP advocacy and policy, practice implementation of medical home, financing and payment, and more. Access the resources here.
The Coordinating Center on Epilepsy Advisory Committee Education Workgroup recently enhanced and updated the content on the AAP parenting website.

**How to Support a Child with Epilepsy**

**Seizures and Epilepsy**

**Epilepsy in Children: Diagnosis & Treatment**

This new content was highlighted on the home page of HealthyChildren.org and also hit the social media outlet.

Here are some tweets:

- Seizures can be frightening when they happen. Stay calm and use these tips to help your child. [ow.ly/EtuF7](https://ow.ly/EtuF7)

- Children with epilepsy can live full, active lives. Here's how. [ow.ly/EFsBX](https://ow.ly/EFsBX) #epilepsyawareness
## December | January | February
### Calendar of Events

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<th>CYE TeleECHO Clinics</th>
<th>MCHB CYE Project Grantee Calls</th>
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<td>12/2/14 Cognitive Rehab Aspects For Kids With Seizures</td>
<td>12/04/14 11am CST</td>
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<td>12/9/14 When To Refer</td>
<td>01/08/15 11am CST</td>
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<td>12/16/14 Transitioning to Adult Care</td>
<td>02/05/15 10am CST</td>
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<td>01/20/15 Cerebral Palsy</td>
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<td>02/03/15 Learning/Behavior Disorders and Needs</td>
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<td>02/17/15 Reproductive Health</td>
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<th>Project ECHO Expansion Grantee Call</th>
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<td>Advisory Committee Call</td>
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<td>MetaECHO Conference Call</td>
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**H O L I D A Y S**

Happy from the Coordinating Center on Epilepsy

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN

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