A message from our Program Chair/Medical Director:

One in 26 persons in the United States is estimated to have epilepsy. Epilepsy is more than seizures; there are many medical and psychosocial ramifications for the individual and families. Although we have come a long way in treating seizures with novel anti-seizure medications, specialized diets, surgery and brain stimulation, much still needs to be done to improve the lives of several children and youth who are affected by epilepsy. In the short time since its inception, the Center and the various state projects have addressed some of the significant gaps in caring for this population.

I am amazed at the grantees work and impressed by the scope of their projects. Despite the diverse projects, every conference call reminds me of the commonality of our mission and how our individual projects serve to reach those goals. Every step we take as individual grantees and with the Center brings us closer to bridging the gaps that still exist in epilepsy care for children and youth.

~Sucheta M. Joshi, MD, MS, FAAP~
Clinical Associate Professor
Pediatric Neurology
Ann Arbor, Michigan

Welcome!

Welcome to the inaugural Coordinating Center on Epilepsy (Center) newsletter! This newsletter is designed to provide updates about Center activities. This is an exciting and important project to serve children and youth with epilepsy.

The mission of the Center is to establish a comprehensive community-based system of care that ensures that children and youth with epilepsy have complete access to pertinent supports and services that they require.

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Meet the AAP Staff!

Program Director:
Ramesh Sachdeva MD, PhD, MBA, JD, FAAP

Program Co-Director:
V. Fan Tait, MD, FAAP

Program Manager:
Trisha M. Calabrese, MPH

Program Coordinator:
Doris Santos

Director, Division of Technical and Medical Services:
Ray Koteras, MHA

Manager, Section on Neurology:
Lynn Colegrove, MBA

Program Director, QuINN:
Keri Thiessen, MEd

Meet the Maternal Child Health Bureau Staff!

Public Health Analyst
Sadie Silcott, MBA, MPH
Division of Services for Children with Special Health Needs

Meet the Grantees

The HRSA Epilepsy Program integrates public health, epilepsy affiliates, and providers to develop more seamless services across primary and specialty care, educational services, and other community resources. The following is a current list of grantees and clicking here will enable you to view their projects:

The Cleveland Clinic Foundation

Epilepsy Foundation of New Jersey Corporation

Epilepsy Foundation of Texas

Epilepsy Foundation of Western Pennsylvania

Michigan Department of Community Health

New Hampshire Department of Health and Human Services

The Parents Place of Maryland
The Coordinating Center on Epilepsy

Cleveland Clinic - Project CARE 4 Epilepsy

Cleveland Clinic’s Project CARE 4 Epilepsy is pleased to offer two new programs for patients and families. These programs are designed to improve care coordination, increase social support, provide education, and increase engagement for teens with epilepsy and their families.

The Cleveland Clinic Epilepsy Center is proud to announce online Facebook groups that offer resources to help teens with epilepsy and their families.

For Teens – E-BEATS: Epilepsy Buddies Encouraging Advocating Telling our Stories

For Parents – CEOS: Coping with Epilepsy Online Support

How to Join:

Please contact:
Laura Neece-Baltaro, MBA (for adults)
Jane Timmons-Mitchell, PhD (for teens).

Finally, please join one of our monthly educational webinars regarding pediatric epilepsy. The next Webinar “Taking Epilepsy to School” by Laura Neece Baltaro, MBA and Dr. Tatiana Falcone will be held on Thursday, July 10, 2014 at 12 noon EST.

Register Now!

Funding for the Center is provided by the Health Resources Services administration (Grant 98MC26260).

Regional Access Collaborative: Improving Diagnosis, Treatment and Services for Children and Youths with Epilepsy

The Epilepsy Foundation of New Jersey, the Epilepsy Foundation of Connecticut, and the Epilepsy Foundation of Northeastern New York, are taking a tri-state approach to addressing access to care issues for children and youth with epilepsy by utilizing a provider training tool Improving Accurate Diagnosis & Treatment of Epilepsy: A Training for Pediatric Practice.

To date, the team conducted 9 parent focus groups throughout the three states. These groups have already demonstrated positive outcomes, including the creation of a parent support group and involvement with the summer basketball camp. This project was recently shared at the New Jersey AAP Chapter meeting.

Project Director: Liza Gundell
1-609-392-5621
1-800-336-5843
lgundell@efnj.com
The L.E.A.P. to Understanding – Pennsylvania Local Epilepsy Awareness Project

In the summer and fall of 2013, as part of a Health Resources and Services Administration (HRSA) grant, the Epilepsy Foundation of Western/Central Pennsylvania (EFWCP), in collaboration with the Epilepsy Foundation of Eastern Pennsylvania, partnered with the Bureau of Family Health, PA Department of Health, the PA Elks Home Services Program, Special Kids Network and the PA Academy of Pediatrics Medical Home Initiative on a rural outreach/community engagement effort to better understand the needs and service gaps of children and youth with epilepsy and their families. This historic event, known as the L.E.A.P. to Understanding – the Local Epilepsy Awareness Project, was accomplished by holding 14 (focus groups) in each of the six Department of Health, Community Health Districts. The meetings were facilitated by parent-led teams consisting of the Bureau of Family Health, Special Kids Network Regional Coordinators (parents of children and youth with special healthcare needs) and parents of children/youth with epilepsy.

Across the project, 192 participants (68 family members, 92 community members) attended focus groups. The remaining 42 family members participated through phone interviews. The information obtained during these meetings are included in a final report outlining outcomes, recommendations, and strategies to increase awareness and understanding of epilepsy and increase access to care for children and youth with epilepsy in more rural, medically underserved areas of the state.

The project resulted in a number of immediate outcomes that show tremendous promise for short and long term change. The accomplishments included: (1) increased the capacity of parent leaders, (2) created a replicable protocol for Community Conversations, (3) increased awareness and understanding of epilepsy issues; (4) established thirteen regional Communities of Practice in six regions; (5) established a statewide Community of Practice; and (6) identified needs, existent services, and service gaps for children, youth and families impacted by epilepsy.

Initial areas of focus for the regional teams include:
- Networking and support opportunities for parents and individuals
- Accessible pediatric neurology services in rural areas
- Epilepsy awareness and education for primary care practices, first responders and other community organizations
- Epilepsy education in schools
- Pediatric neurology telemedicine
- Transportation for Amish/others to specialists

Additionally, the L.E.A.P. project is a major focus of the current EFWCP State and Regional Approaches to Improving Access to Services for Children/Youth with Epilepsy HRSA grant supported by the AAP Coordinating Center on Epilepsy. The final L.E.A.P. report will inform the development and enhancement of programs and services for individuals with epilepsy/seizure disorders and their families for years to come.

For additional information, please contact Rick Boyle:

- Epilepsy Foundation of Western/Central PA
- 1-800-361-5885
- rboyle@efwp.org
The AAP Section on Neurology and Quality Measures for Epilepsy

The Section on Neurology (SONu) was recently invited to nominate an AAP/SONu representative to participate in a workgroup that will review the existing American Academy of Neurology (AAN) epilepsy measures and develop new epilepsy measures for use in quality improvement, pay for reporting, accountability, and/or maintenance of certification performance in practice programs. Section member Edwin Trevathan, MD, MPH, FAAP, a pediatric epileptologist and Dean of the College for Public Health and Social Justice at St. Louis University, serves as the AAP/SONu representative for this important initiative. AAP involvement will ensure that the measures include the pediatric perspective. Once approved and published, the AAN measure sets will be available online free of charge.

For more information, visit the Section website or contact Lynn Colegrove, Section Manager.

~Peter B. Kang, MD, FAAP~
Chair, Executive Committee
AAP Section on Neurology

NCE 2014 SONu-Sponsored Programs

F1092 - Basics of Seizure Medicines: What General Pediatricians Need to Know Selected Short Subject.
New medicines for treating seizures are being introduced to market nearly once per year. As a result, there is a whole new set of side effects to know. There is an increasing realization of long-term side effects of older medicines, as well. Examples include bone health, reproductive health (including teratogenesis) and electrolyte abnormalities, among others. Come listen to our experts discuss what general pediatricians need to know about seizure medicines.
Faculty: Raman Sankar, MD, PhD
Saturday, October 11, 2014, 2:00 – 2:45 pm

X2045- Shake, Rattle and Roll.
➤➤ Repeats as A2103 – Sunday, 2:00 – 3:00 pm Audience Response Case Discussion. What was that? A seizure, breath-holding spell, myoclonus, shuddering attack, migraine, tic, faint, or something else? Come learn how to sort out and identify the spells that will present in your practice, and learn what is neurological, cardiac, or even benign.
Faculty: Sucheta Joshi, MD, FAAP and Sankar Raman, MD Saturday, October 11, 2014, 8:30 – 10:00 am

F3119- One Seizure, Two Seizures: What Do I Do Now?
➤➤ Repeats as F4084 - Tuesday, October 14, 2014, 4:00 – 4:45 pm Selected Short Subject. When a child presents with a first or second seizure both temperature and anxiety can be high. Do you know how to evaluate and manage the child with a first or second febrile seizure or seizure without fever? Come review the most current approach for handling a child with new-onset seizures, and review AAP guidelines.
Faculty: Courtney J. Wusthoff, MD
Monday, October 13, 2014, 3:00 – 3:45 pm

Click here to register online!
Project ECHO® - Clinical Launch - Child/Youth Epilepsy teleECHO™ Clinic

The AAP partnered with the University of New Mexico Project ECHO (Extension for Community Healthcare Outcomes) model of health care delivery and education to expand existing capacity to provide best practice care for children and youth with epilepsy (CYE) in rural and underserved areas of New Mexico as well as to monitor outcomes to ensure quality of care. Project ECHO creates partnerships between primary care providers (PCPs) in rural and underserved areas and specialty care providers at academic medical centers that allow for the sharing of new knowledge in real time. Using state-of-the-art telehealth technology, clinical management tools, and case-based learning, Project ECHO trains and supports PCPs in the community to develop knowledge and self-efficacy on diseases and conditions not usually considered within their scope of practice. To learn more about Project ECHO and its success with Hepatitis C in the adult population, click here.

On June 3rd, the University of New Mexico launched the inaugural CYE teleECHO clinic. More than 30 participants from across New Mexico joined! Join the team, Tuesdays from 12pm—1pm Mountain Time. Here is the Project ECHO® Calendar.

HOW TO JOIN/PARTICIPATE:

**Joining via Video:**
To download the software used to attend via video please go here and click on the Download link at the bottom of the page.

PC/Mac - You'll need to allow the file download and then run the file. Once Zoom is installed it should open automatically.

- Click on Host a Meeting
- Click on Login with SSO
- Enter https://echo.zoom.us in SSO Site URL field and press continue
- Enter your IECO Username (your email address) and password and click Login
- Click on Join a Meeting
- Enter 606 060 6060 in the Meeting ID Field and click Join

To join via video from Polycom, Cisco, Tandberg:

Dial: 4.34.125.153 (US East) or 4.35.64.153 (US West)

Meeting ID: 606 060 6060

**Audio:**
If you’re unable to join via video:

Dial Toll Free: +1 (888) 974-9888

Enter the Meeting ID: 606 060 6060

Press # to skip the Participant ID entry

Press *6 to mute your line when not speaking
Quality Improvement Innovation Networks (QuIIN)

The AAP Quality Improvement Innovation Networks (QuIIN) is home to multiple pediatric quality improvement networks designed to improve care for children and their families in both the inpatient and outpatient settings. QuIIN serves as the infrastructure for pediatric improvement networks by providing staff, financial, and standard operating systems to the Value in Inpatient Pediatrics (VIP) Network and the Practice Improvement Network (PIN).

Inaugural Advisory Committee Meeting!

The Advisory Committee (AC) provides leadership and strategic oversight for all of the Center activities, including the technical assistance infrastructure, which serves as the educational and systems arm of the Center. The AC also serves as a conduit of information to other stakeholders, including other interested parties and membership bodies, where appropriate.

The AC held their first inaugural meeting in Washington, DC on June 11th at the AAP Department of Federal Affairs Office. Learn more about the Center Leadership and Committee Members here.
## June’s Calendar of Events

### Schedule of Events

| June 3: | Project ECHO® - Clinical Launch - Child/Youth Epilepsy (CYE) teleECHO™ Clinic |
|        | 12pm-1pm MT |
| June 5: | MCHB CYE Project Grantee Monthly Conference Call |
|        | 2pm-3pm CST |
| June 10-11: | Program Advisory Committee Meeting, Washington, DC |
| June 10, 17 & 24: | Project ECHO® - CYE teleECHO™ Clinic |
|        | 12pm-1pm MT |
| June 24: | Project ECHO UNM WEBINAR — Epilepsy and the Primary Care Physician — 12pm MT |

**Presented by:**
Sucheta Joshi, MD FAAP

### June 2014 Calendar

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**CHECK THIS OUT!**

Be sure to check the latest calendar [here](#) for updates!
Join us on Sharepoint!

Contact Trisha M. Calabrese today if you need assistance with logging into the Center’s Sharepoint site! Let’s start sharing!

Did you enjoy the newsletter? Let us know your thoughts!