

NATIONAL COORDINATING CENTER FOR EPILEPSY

*Fostering strategic approaches to quality health care for
children and youth with epilepsy*

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AMERICAN ACADEMY OF PEDIATRICS

MISSION

To attain optimal physical, mental and social health and well-being for all infants, children, adolescents and young adults.

AMERICAN ACADEMY OF PEDIATRICS

- **United States (and Globally) 67,000+ pediatricians**
 - Experts involved in Committees, Councils, and Sections
 - Including pediatric neurology; pediatric neurosurgery; children with special health care needs; community pediatrics; rural health; school health; quality improvement
- **Local Outreach**
 - 59 chapters in the US working to achieve AAP goals in their states/communities
- **Medical Home; Bright Futures**
- **Partnerships with National Organizations**
 - Child Neurology Society, American Academy of Neurology, American Epilepsy Society, Epilepsy Foundation, National Institutes of Health



AAP DIVISION OF INNOVATION

- **Coordinating Center for Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy: 2013-2019**
 - HRSA/MCHB CYE Grantees
 - Access Improvement and Management for Epilepsy with Telehealth (AIM-ET) pilot project
 - AAP Epilepsy and Comorbidities ECHO
- Overseen by multi-disciplinary Advisory Committee representing various stakeholders in the care of CYE

NATIONAL COORDINATING CENTER FOR EPILEPSY

- The purpose of this program is to improve access to **coordinated** and **comprehensive quality care** for children and youth with epilepsy with an emphasis on populations experiencing health disparities and residing in medically underserved/rural communities:
 - Transitions
 - Telehealth
 - Learning Collaborative

NATIONAL COORDINATING CENTER FOR EPILEPSY: GOALS

- **Goal 1:** Implement a **National and grantee** program infrastructure to ensure that CYE obtain sustainable, coordinated and comprehensive quality care
 - **Support 7 state grantees and their 69 clinical sites that serve ~25,500 CYE**
- **Goal 2:** Develop state-of-the-art, high quality, **quality improvement** (QI) learning collaboratives and protocols for grantees to ensure they have access to relevant evidence-based models, best practices, and strategies

NATIONAL COORDINATING CENTER FOR EPILEPSY: GOALS

- **Goal 3:** Leverage **telehealth** to increase access to care for CYE in underserved areas/populations and increasing the PCP capacity
- **Goal 4:** Develop and implement a **comprehensive evaluation methodology** to support and monitor outcomes of the Coordinating Center and grantees implementation, evaluation, and spread of evidence-based epilepsy-related services

ACCESS IMPROVEMENT AND MANAGEMENT FOR EPILEPSY WITH TELEHEALTH (AIM-ET)

- **Partner pediatric neurologists with pediatric practices** in underserved and rural areas to implement telehealth:
 - University of Utah
 - Stanford University
 - Alabama Department of Public Health/University of Alabama
- Collecting **data to assess outcomes on patient satisfaction**, missed work/school hours, mileage

PROJECT ECHO

- The ECHO (Extension for Community Healthcare Outcomes) model™ is a tele-mentoring hub and spoke platform that leverages technology to bring together specialty care providers at academic medical centers (hub) and healthcare professionals in local communities (spokes)

AAP ECHO SUPERHUB



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CHILDREN AND YOUTH WITH EPILEPSY TeleECHO

- In 2013, the AAP partnered with the ECHO Institute to launch the **CYE TeleECHO pilot project** to increase access to care for CYE in New Mexico
 - Launched 4 other CYE ECHOs: CA, IL, NY, KS/MO
- Developed **standardized curriculum** using evidence-informed clinical guidelines and practices for the management of epilepsy; integrated team-based care in a patient/family-centered medical home

AAP EPILEPSY AND COMORBIDITIES ECHO

- Incorporating the **CYE TeleECHO standardized curriculum** and the **American Academy of Neurology (AAN) quality measurement set for epilepsy** to facilitate improvement at the practice-level for:
 - Early and accurate diagnosis
 - Reduction and monitoring of anti-seizure therapy
 - Improved care coordination
 - Patient-centered care
 - Timely and appropriate referrals
 - Health care transitions

RECRUITMENT

- Recruiting up to **20 pediatric primary care practices** providing services to pediatric patients and serving diverse communities via a 'Call for Proposals'
- Multi-disciplinary teams to lead practice QI efforts:
 - Physician champion/MOC local leader
 - Nurse practitioner
 - Additional team member such as front office, practice manager, medical assistant, or care coordinator

RECRUITMENT

- **Eligibility criteria:**
 - Provide pediatric primary care, including at least 10 visits with CYE per month
 - Secure approval from practice leadership to participate in this project
 - Identify a core QI team responsible for providing leadership and oversight within the practice for the project
 - Agree to all participation requirements
- **Selection criteria includes:**
 - A desire and capacity for process improvement to improve access to quality healthcare for CYE
 - Pediatric practices representing communities with underserved populations will be given priority



Epilepsy Homepage

Epilepsy Overview

Access to Care

Families and Caregivers

About the Center

National Coordinating Center for Epilepsy

Fostering strategic approaches to improving access to quality health care for children and youth with epilepsy.

Epilepsy Compendium

Download the Epilepsy Compendium - a continually updated guide of epilepsy resources.

Find out more



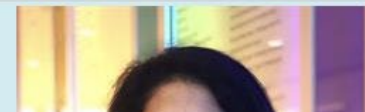
1 2 3



Access to Care

Click to find resources for increasing access to quality healthcare and improving care coordination for children and youth with epilepsy. ➔

MESSAGE FROM OUR CHAIR





Checklist for Providing Care to Children and Youth with Epilepsy (Initial Diagnosis)

The purpose of this document is to provide primary care providers with the information necessary to provide care to children and youth with epilepsy, as well as to successfully transition children and youth with epilepsy to another health care provider (e.g. another pediatric primary care provider, adult primary care provider, or subspecialist).

<p>HISTORY:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Document seizure type(s) and frequencies (seizure diary/Seizuretracker)* <input type="checkbox"/> Medication history (current and previous seizure treatments and side effects) <input type="checkbox"/> ER Visits and Hospitalizations, history of status epilepticus <input type="checkbox"/> School Performance (ADHD, learning Challenges, 504 plan or IEP) <input type="checkbox"/> Mood / behavior of child <input type="checkbox"/> ADL capacity <input type="checkbox"/> Who lives in the home? <input type="checkbox"/> Perinatal History (gestational age, birth weight, need for resuscitation and/or NICU; history of neonatal seizures) <input type="checkbox"/> Other medical issues <input type="checkbox"/> History of Head Trauma <input type="checkbox"/> History of CNS Infections <input type="checkbox"/> History of febrile seizures <input type="checkbox"/> Does the family have a history of epilepsy <ul style="list-style-type: none"> <input type="checkbox"/> complete a genogram <input type="checkbox"/> consider ordering genetic testing if the etiology of epilepsy is not clear—Microarray, epilepsy gene panel, or whole exome sequencing 	<p>TOOLS:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Templates (page 51+) <input type="checkbox"/> Adverse Effects Associated with Psychiatric Medications <input type="checkbox"/> Medications <input type="checkbox"/> First unprovoked seizure (provider) <input type="checkbox"/> Treatment Guide (Families) <input type="checkbox"/> Initial History Form <ul style="list-style-type: none"> <input type="checkbox"/> Family History Tools <input type="checkbox"/> 11-14 <input type="checkbox"/> 15-21
<p>TESTING AND DIAGNOSIS</p> <ul style="list-style-type: none"> <input type="checkbox"/> Labs: Explain the necessary tests to effectively diagnosis the epilepsy/seizure disorder <ul style="list-style-type: none"> <input type="checkbox"/> MRI _____ (Date) <input type="checkbox"/> CT SCAN _____ (Date) <input type="checkbox"/> EEG _____ (Date) <input type="checkbox"/> Blood – <ul style="list-style-type: none"> <input type="checkbox"/> Ca, CMP _____ <input type="checkbox"/> 25 OH Vitamin D3 level _____ <input type="checkbox"/> CBCPD _____ <input type="checkbox"/> Other _____ Genetic Testing _____ 	<p>TOOLS:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Recommendations for the Assessment of Laboratory Studies (Providers) <input type="checkbox"/> Diagnosing the Cause of Status Epilepticus in Children (Families)



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From the AAP | For Your Practice | New Research | Upcoming Events

April 2018

The information in this email is selected for its value and relation to epilepsy and does not represent an endorsement or an official opinion or position of the American Academy of Pediatrics.
If you have questions or comments, email shueneke@aap.org.



**BLOOM WHERE
YOU ARE
PLANTED.**

-St. Francis de Sales

New!

We are pleased to announce new branding to encompass our expanding focus. The **National Coordinating Center for Epilepsy** fosters strategic approaches to improving access to quality health care for children and youth with epilepsy by collaborating with organizations across the United States.

For questions about the information in this eNews, individualized resources, or to request monthly topics, contact Sarah at shueneke@aap.org.

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OPPORTUNITIES FOR COLLABORATION

- Convene for a quarterly **CYE Stakeholder Forum** to discuss successes, challenges, and opportunities:
 - **April 16, 11:00 am CST**
- Share **AAP Epilepsy and Comorbidities ECHO** recruitment information and encourage pediatric primary care practices to apply
 - **Deadline: April 18**



THANK YOU!



Questions, comments, or would like to collaborate?

Sarah Hueneker | shueneker@aap.org

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