AAP EPILEPSY AND COMORBIDITIES ECHO

SEIZE THE MOMENT

NATIONAL COORDINATING CENTER FOR EPILEPSY

Fostering Strategic Approaches to Improve Access to Quality Health Care for Children and Youth with Epilepsy
INTRODUCTION

The American Academy of Pediatrics, National Coordinating Center for Epilepsy is thrilled to present the AAP Epilepsy and Comorbidities ECHO Toolkit!

The goal of this “all teach, all learn” innovative approach is to help improve access to quality health care for children and youth with epilepsy (CYE) in your practice and across the United States utilizing the ECHO (Extension for Community Healthcare Outcomes) model™. Project ECHO® is a telementoring program designed to create communities of learners by bringing together health care providers and subject matter experts using widely available videoconferencing technology, clinical management tools, didactic presentations and case-based learning. As part of this program, participants joined a bi-directional virtual knowledge network learning from experts and other pediatric practices, gaining access to evidence-based and capacity-building resources to improve management of patients with epilepsy.

This toolkit contains tools and resources, lessons learned, and data gathered from the AAP Epilepsy and Comorbidities ECHO, which was implemented April to December 2018 among seven pediatric practices. These tools and resources may be adapted for your practice to help guide improvement in the care of patients with epilepsy. This toolkit may also be useful for organizations interested in implementing an ECHO focused around quality improvement (QI).

For more information, please reach out to the AAP National Coordinating Center for Epilepsy staff at epilepsy@aap.org or aapecho@aap.org or visit our website at www.aap.org/epilepsy.

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U23MC26252, Awareness and Access to Care for Children and Youth with Epilepsy/ cooperative agreement. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the U.S. Government.
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THE PROJECT TEAM

MEDICAL DIRECTOR/FACULTY: Sucheta Joshi, MD, MS, MPH, FAAP is an epileptologist at Michigan Medicine, University of Michigan, who provided overall project oversight and guidance to project staff.

QUALITY IMPROVEMENT CONSULTANT/FACULTY: Kari Gali, DNP, CPNP, CPHQ is the quality improvement consultant for the AAP Epilepsy and Comorbidities ECHO. Through her clinical transformation experience at Cleveland Clinic, Dr Gali lead teams through quality improvement processes, was responsible for final review and signed off on participant attestation forms and resolution of participation disputes, if needed.

ECHO MANAGER: Amy Shah, MPH is the ECHO Program Manager, and was a primary contact for AAP Epilepsy and Comorbidities ECHO. She is responsible for ensuring fidelity to the ECHO model as well as providing technical assistance to the participating practices who progressed through the ECHO program. Questions about MOC requirements, quality improvement tools and resources, project updates, and other general questions can be directed to Amy at ashah@aap.org or (630) 626-6486.

MANAGER, NATIONAL COORDINATING CENTER FOR EPILEPSY: Sarah Hueneke, MPH is the Manager for the National Coordinating Center for Epilepsy and was a primary content contact for the AAP Epilepsy and Comorbidities ECHO. Questions related to epilepsy and the National Coordinating Center for Epilepsy can be directed to Sarah at shueneke@aap.org or (630) 626-6424.

EVALUATION CONSULTANT: Linda Radecki, MS served as the evaluation consultant for the AAP Epilepsy and Comorbidities ECHO program.

MULTI-DISCIPLINARY FACULTY: The multi-disciplinary expert faculty attended every ECHO session and were available for guidance and recommendations throughout the project.

Pattie Archuleta is a family engagement and training specialist for the children and youth with epilepsy and other seizure disorders program at Maryland Coalition of Families. Expertise: Family engagement

Larry Brown, MD, FAAP is a pediatric neurologist at the Children’s Hospital of Philadelphia. Expertise: Neurology; Epilepsy

Eve Kimball, MD, FAAP is a practicing primary care pediatrician and founder of All About Children Pediatric Partners in Pennsylvania. Expertise: Primary care; Quality improvement
**Peggy McManus, MHS** is president of The National Alliance to Advance Adolescent Health, an organization that oversees the HRSA/MCHB cooperative agreement *Got Transition*. **Expertise:** Health care transition; Quality improvement

**Eve-Lynn Nelson, PhD** is a professor of behavioral pediatrics at University of Kansas Medical Center. **Expertise:** Behavioral health

**Patience White, MD, FAAP** is an adult and pediatric rheumatologist and is co-director of the HRSA/MCHB cooperative agreement *Got Transition*. **Expertise:** Health care transition; Quality improvement

**David Wood, MD, FAAP** is a practicing pediatrician and chairman of the Department of Pediatrics at East Tennessee State University Quillen College of Medicine. **Expertise:** Primary care; Health care transition
BACKGROUND AND RATIONALE

In 2012, the Institute of Medicine (IOM) released the Epilepsy across the Spectrum: Promoting Health and Understanding report. The report summarized epilepsy research disparities and highlighted specific areas where further research is needed, including the extent of epilepsy, consequences, comorbid conditions, and outcomes of epilepsy.

There are approximately 470,000 children aged birth to 17 years with epilepsy, the most common childhood neurologic condition in the United States.\(^1\)\(^2\) Despite ongoing research and treatment advances, approximately one-third of individuals with epilepsy “continue to have difficult-to-control seizures.” The clinical spectrum of children and youth with epilepsy (CYE) varies as some forms of epilepsy can have dramatic effects on brain development in early childhood and lead to poor functioning later in life. There are many etiologies for the disease that range from genetic and metabolic conditions to infections, trauma, and developmental brain disorders. Common comorbidities among people with epilepsy include somatic (ie, fractures, asthma, diabetes, and heart disease), neurological (ie, stroke, Alzheimer’s disease, autism spectrum disorders, chronic pain), and mental health conditions (ie, mood disorders, attention deficit hyperactivity disorders, anxiety disorders, suicidality). In addition to these concerns, it is estimated that 1 in 4,500 children with epilepsy are victims to sudden, unexpected death (SUDEP).\(^3\)

Prevalence may be underestimated due to underreporting associated with repercussions and stigma in disclosing epilepsy. People with epilepsy have poorer overall health status, impaired intellectual and physical functioning, a greater risk for accidents and injuries, and negative side effects from seizure medications. They are also more likely to be unemployed or unable to work, have low annual household incomes, obese and physically inactive, and to smoke. It is estimated that the annual cost (direct and indirect) of epilepsy in the United States is $15.5 billion.\(^4\) Additionally, the Bureau of Labor and Statistics revealed that in 2018, "19.1 percent of persons with a disability were employed, the U.S. Bureau of Labor Statistics reported today. In contrast, the employment-population ratio for those without a disability was 65.9 percent.\(^5\)

Furthermore, primary care providers (PCPs) are often the first point of contact for a child with new-onset seizures but feel inadequately trained to manage epilepsy. According to a 2018 American Academy of Neurology (AAN) Insight Report, there are only 1,327 child neurologists in the US – at least 20% below the national need – which results in limited access to care for CYE, especially in rural and underserved communities.\(^6\) A national shortage of pediatric neurologists results in long wait times, which can impact effective management of epilepsy.

This project aligns with the 2014 American Academy of Neurology (AAN) Measurement Set for Epilepsy, which is endorsed by the American Academy of Pediatrics (AAP), American Epilepsy Society (AES), Child Neurology Foundation (CNF), and the Epilepsy Foundation (EF).
PROJECT OVERVIEW

This project was funded by a cooperative agreement between the Health Resources and Services Administration (HRSA)/Maternal Child Health Bureau (MCHB) and AAP to foster strategic approaches to improve access to quality health care for CYE. Building on the success of previous ECHO programs, the 2014 AAN Measurement Set for Epilepsy was used as a framework to integrate quality improvement (QI) to generate sustainable change among pediatric practices through evidence-based processes to reach desired outcomes including:

- Early and accurate diagnosis
- Improved care coordination
- Patient-centered care
- Reduction and monitoring of anti-seizure therapy
- Patient education
- Health care transitions
- Timely and appropriate referrals

THE ECHO MODEL

The ECHO model is an innovative, hub and spoke telementoring program designed to create virtual knowledge networks bringing together health care providers and subject matter experts using brief lectures and case-based presentations using videoconferencing. These formalized partnerships increase capacity for PCPs to identify, treat, and manage the care of their patients within the medical home. Using state-of-the-art technology, clinical management tools, and case-based learning, PCPs develop knowledge and self-efficacy on diseases/conditions encountered within their scope of practice.

To view a brief summary on Project ECHO, click here.

To learn more on the history of Project ECHO and its’ impact, view Dr Sanjeev Arora’s presentation during the AAP National Conference and Exhibition in 2015.

ANATOMY OF AAP EPILEPSY AND COMORBIDITIES ECHO

Each monthly session was conducted in the following format:

- Introductions (5 minutes)
- Brief lecture by faculty (15-20 minutes)
- Lecture presentation Q&A (5 minutes)
- Patient case presentation and Q&A (20-25 minutes)
- Closing remarks
PROJECT IMPLEMENTATION

Pre-Launch
- IRB Application
- Recruitment
- Curriculum/Case Form Development
- Selection of QI Measures
- CME, MOC 2 & 4 Applications
- Data Collection Tool
- Evaluation Plan

Implementation
- Monthly ECHO Sessions
- Submission of De-identified Cases
- QI Methodology Including:
  - Practice Team Huddles
  - PDSA Cycles
  - Checklists

Post-Launch
- Program Evaluation Including:
  - Participation Data
  - Post-session CME Surveys
  - Retrospective Survey
  - Focus Groups
  - Demonstrating Program Impact Including:
    - Manuscript and Abstract Development
PROJECT CURRICULUM

The AAP Epilepsy and Comorbidities ECHO didactics were adapted from curricula pilot tested in the 2016 CYE ECHO program.

1 Epilepsy Overview
2 Workflow Processes and the PDSA Cycle
3 Comorbidities of Epilepsy
4 Testing and Diagnosis of Epilepsy
5 Medication Treatment
6 Safety and Education for Epilepsy
7 Role of PCP in a Medical Home Setting
8 Transition to Adult Care

CASE PRESENTATION FORM

As part of the ECHO model, the case presentation serves as a tool to educate providers on patient interview questions, exams, monitoring specific assessments and treatment modalities that are consistent with best practices. In the AAP Epilepsy and Comorbidities ECHO, each practice team submitted two cases and had the opportunity to present at least one case on the network during the project period.

The presentation was typically 5-10 minutes long and described any current or previous patients across the pediatric age range where:

- Symptoms may be epilepsy-related, but not sure and would like to seek guidance on how to sort it out symptomatically, historically or from a difficult conversation standpoint (is it epilepsy or not epilepsy and what should I do?).
- It is epilepsy, but not sure how to proceed.

Please refer to Appendix A for the case presentation form template. The template was developed to identify core elements of the case to provide meaningful feedback and organized as a guide to present the case to the network.
MOC AND CME REQUIREMENTS

Maintenance of Certification (MOC) and Continuing Medical Education (CME) is for physicians, health care professionals, including nurses and physician assistants, who need Category 1 Credit to maintain their physician or health care provider licenses. Building on lessons learned from previous ECHO programs, it was determined that offering MOC and CME credits at no cost would maintain engagement of participants. MOC and CME can be offered in your program through the AAP by submitting an application.

ACCREDITATION AND DESIGNATION

The following verbiage was approved for use by the AAP MOC program for use in the AAP Epilepsy and Comorbidities ECHO only. If your application is approved, the AAP MOC program will provide language appropriate to your project.

*AMA PRA Category 1 Credit(s)*

- The American Academy of Pediatrics (AAP) is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for physicians.
- The AAP designates this live activity for a maximum of 8.0 *AMA PRA Category 1 Credit(s)*. Physicians should claim only the credit commensurate with the extent of their participation in the activity.
- This activity is acceptable for a maximum of 8.0 AAP credits. These credits can be applied toward the AAP CME/CPD Award available to Fellows and Candidate Members of the American Academy of Pediatrics.
- The American Academy of Physician Assistants (AAPA) accepts certificates of participation for educational activities certified for *AMA PRA Category 1 Credit* from organizations accredited by ACCME. Physician assistants may receive a maximum of 8.0 hours of Category 1 credit for completing this program.
- This program is accredited for 8.0 NAPNAP CE contact hours of which 0 contain pharmacology (Rx) content, (0 related to psychopharmacology) (0 related to controlled substances), per the National Association of Pediatric Nurse Practitioners (NAPNAP) Continuing Education Guidelines.
**MOC PART 2 POINTS**
The following verbiage was approved for use by the AAP MOC program for use in the AAP Epilepsy and Comorbidities ECHO only. If your application is approved, the AAP MOC program will provide language appropriate to your project.

Successful completion of this CME activity, which included participation in the activity, with individual assessments of the participant and feedback to the participant, enabled the participant to earn **8 MOC points** in the American Board of Pediatrics’ (ABP) Maintenance of Certification (MOC) program. It was the CME activity provider’s responsibility to submit participant completion information to ACCME for the purpose of granting ABP MOC credit.

*If participants did not successfully complete all components of the activity and evaluation, ABP MOC Part 2 Points would not be awarded; partial credit would not be provided.*

Please note: completion data was shared with the ABP through the ACCME PARS system within 30 days of successful completion. This includes the name of the activity and provider; participant name; participant’s ABP ID number; participant’s DOB; date of completion of the activity; the PARS activity identifier; ABP MOC Part 2 credit statement and number of MOC points awarded. To claim both CME credits and MOC Part 2 points, participants needed to complete short evaluation assessments within 48 hours of the conclusion of the ECHO project – 8 sessions (December 14, 2018).

**MOC PART 4 POINTS**
The following verbiage was approved for use by the AAP MOC program for use in the AAP Epilepsy and Comorbidities ECHO only. If your application is approved, the AAP MOC program will provide language appropriate to your project.

Improving Professional Practice and Quality Improvement (Part 4) of MOC is designed to help assess and improve the quality of patient care and processes that lead to improved child health. Per program requirements, physicians were eligible to claim **25 MOC 4 points** if meaningful participation was demonstrated. Meaningful participation is defined as having an active role in the project as follows:

- Be intellectually engaged in planning and executing the project.
- Implement the project’s intervention (the changes designed to improve care).
- Review data in keeping with the project’s measurement plan.
- Collaborate actively by attending team meetings.

Furthermore, practices needed to conduct the following:

1. Submission of:
   - Data from 10 consecutive patient charts into QIDA for each of eight (8)
consecutive months

b. Submit and/or present two cases for problem solving and guidance.
c. Retrospective survey via Survey Monkey

2. Participate in:
   a. Eight teleECHO sessions
   b. Eight ECHO practice team huddles. QIDA run charts for the practice and ideas for tests of change should be discussed by ECHO practice team members

QUALITY IMPROVEMENT

PRACTICE TEAM MEETINGS

Per project requirements, recruited practices identified an interdisciplinary team (physicians, nurses, medical assistants, practice administrator, etc.) led by a physician champion to discuss the aspects of patient care that are most in need of improvement in the practice in the context of CYE. A “current state” workflow or process map was implemented to help teams identify areas that need improvement (Refer to Page 36 for QI Templates).

Recruited practices for the AAP Epilepsy and Comorbidities ECHO program were encouraged to meet with their core QI team (lead physician, nurse, data administrator) at least once a month to discuss the three fundamental questions from the Institute for Healthcare Improvement (IHI) Model for Improvement (Figure 1):

1. What are we trying to accomplish?
2. How will we know that a change is an improvement?
3. What changes can we make that will result in improvement?

The answers helped the team determine QI aims (Question 1) and related measures (Question 2). Then, selected specific interventions from the change package (Question 3) that the team tested through Plan-Do-Study-Act (PDSA) cycles to see if the team accomplished their aim.

Additionally, the QI consultant held monthly calls with each of the practices to review sustainability to ensure that implementation of activities lead to permanent practice change beyond the ECHO program.

Figure 1: Model for Improvement
To learn more about how to implement team meetings and QI concepts in your practice:

- Practice Transformation
- Implementing Team Meetings and Huddles
- Quality Improvement
- PDSA Cycle Template – Appendix B

**DATA COLLECTION**

Monitoring and measuring office processes and patient outcomes is a critical component of QI. The overarching aim of the AAP Epilepsy and Comorbidities ECHO program was:

*By December 2018, practices participating in the AAP Epilepsy and Comorbidities ECHO will develop and implement effective processes to improve the quality of care for children and youth with epilepsy by increasing screening and discussion of seizure frequency, anti-seizure therapy side effects, safety education, psychiatric/behavioral health disorders, transition to care; referrals to a comprehensive epilepsy center; and optionally counseling of women of childbearing potential with epilepsy.*

**Program Goals and Objectives:**

- Increase documentation of discussion of seizure frequency by 10%.
- Increase documentation of discussion of anti-seizure therapy side effects by 20%.
- Increase documentation of individualized safety education by 30%.
- Increase screening for psychiatric/behavioral health disorders by 5%.
- Increase referrals to a comprehensive epilepsy center by 5%.
• Increase documentation of a transition readiness plan by 20%.

**Per participation requirements, practices were required to do the following each month:**
• Attend all eight ECHO sessions
• Collect and review 10 charts for patients 0-24 years old with a diagnosis of epilepsy (ICD-10 codes included on page 14)
• Conduct a Plan-Do-Study-Act (PDSA) cycle with practice team (Appendix B)
• Participate in 1:1 check-in calls with QI consultant and AAP Staff

**CHART REVIEW**

Practices tracked measures through retrospective chart review to ensure that the changes made have a positive impact on patient care and contributed to progress toward improvement goals. These were tracked monthly using the AAP Quality Improvement Data Aggregator (QIDA) data collection tool, an internal system developed to collect de-identified patient data through chart review. A template of the chart review tool is available in Appendix C.

**Step 1: Collect data from a monthly sample of patient charts (n=10) with a diagnosis of epilepsy using the following codes:**
• G40.xx Epilepsy (otherwise unspecified)
• G40.001 Localization-related (focal) (partial) idiopathic epilepsy and epileptic syndromes with seizures of localized onset, not intractable, with status epilepticus
• G40.011 Localization-related (focal) (partial) idiopathic and epileptic syndromes with seizures of localized onset, intractable, with status epilepticus
• G40.201 Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, not intractable, with status epilepticus
• G40.211 Localization-related (focal) (partial) symptomatic epilepsy and epileptic syndromes with complex partial seizures, intractable, with status epilepticus
• G40.301 Generalized idiopathic epilepsy and epileptic syndromes, not intractable, with status epilepticus
• G40.311 Generalized idiopathic epilepsy and epileptic syndromes, intractable, with status epilepticus
• G40.401 Other generalized epilepsy and epileptic syndromes, not intractable, with status epilepticus
• G40.411 Other generalized epilepsy and epileptic syndromes, intractable, with status epilepticus
• G40.501 Epileptic seizures related to external causes, not intractable, with status epilepticus
• G40.901 Epilepsy, unspecified, not intractable, with status epilepticus
• G40.911 Epilepsy, unspecified, intractable, with status epilepticus
• R56.8 Seizures (otherwise unspecified)
• G40.xx Epilepsy (otherwise unspecified)

**Step 2:** Once this list has been generated, abstract selected measures from charts using systematic random sampling method for guidance.

The total number of monthly charts within the age range (ages 0 to 24 years) was divided by 10. This was the sampling interval for the month. For example, if 40 patients were seen with epilepsy, the sampling interval is 4. The last day of the month was chosen as the starting point for sampling. Using this starting point, each practice chose the next chart based on the sampling interval. In this example, the practice works backward in time from the last day of the month and identifies every 4th visit for a patient seen with epilepsy.

*Note: Practices that did not have the ability to generate an automated internal list of these patients received advice from the QI consultant on how to achieve a representative sample.*
MEASURES

The following measures from the 2014 AAN Measurement Set for Epilepsy were selected due to their alignment with the curricula pilot tested during the 2016 CYE ECHO program. Many of these measures have since been retired and an updated measurement set can be found on the AAN website.

The ECHO program achieved the targeted goals for 5 of the 7 QI clinical measures with statistically significant results for measure #3 (Safety Education), #4 (Screening for Behavioral Health), and #7 (Transitions). Aggregate run charts are provided after each measure.

#1: SEIZURE FREQUENCY

<table>
<thead>
<tr>
<th>Measure Description</th>
<th>Percent of all visits for patients with a diagnosis of epilepsy where the seizure frequency of each seizure type was documented.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>Patient visits with current seizure frequency* documented for each seizure type.</td>
</tr>
<tr>
<td>Denominator</td>
<td>All visits for patients with a diagnosis of epilepsy.</td>
</tr>
<tr>
<td>Denominator Exceptions</td>
<td>Caregiver is unavailable for a patient who is non-communicative or has an intellectual disability.</td>
</tr>
<tr>
<td></td>
<td>Patient or caregiver declines to report seizure frequency.</td>
</tr>
<tr>
<td>Rationale for Measure</td>
<td>The main objective in treating epilepsy is to reduce the frequency of seizures and achieve seizure freedom without side effects. In order to determine whether a patient is seizure-free the seizure frequency must be known. Seizure freedom is associated with improvement in health-related quality of life.</td>
</tr>
</tbody>
</table>

*Current seizure frequency: A record of the exact number of seizures gathered from patient records, journal, or calendar OR the average or typical recent seizure frequency, often expressed as the average daily, weekly, or monthly seizure frequency since the last visit.
Measure 1: Seizure frequency documentation was predicted to increase by 10%; however, ECHO participants collectively achieved a 7.1% increase. Despite these gains, the improvement was not statistically significant. More data and a longer project would increase predictive capability.
### #2: Querying and Intervention for Side Effects of Anti-Seizure Therapy

<table>
<thead>
<tr>
<th>Measure Description</th>
<th>Percent of all patients with a diagnosis of epilepsy with active anti-seizure therapy side effects for whom an intervention was discussed.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>Patients with anti-seizure therapy side effects for whom an intervention* was discussed.</td>
</tr>
<tr>
<td>Denominator</td>
<td>All visits for patients with a diagnosis of epilepsy actively receiving anti-seizure therapy with a side effect noted at time of visit.</td>
</tr>
<tr>
<td>Denominator Exceptions</td>
<td>Patient or caregiver declines to answer questions on anti-seizure medication side effects.</td>
</tr>
<tr>
<td>Rationale for Measure</td>
<td>Anti-seizure medications commonly cause neurological side effects such as sleepiness, dizziness, fatigue, and diplopia. Some anti-seizure medications can cause idiosyncratic side effects such as weight changes, irritability or gastrointestinal issues. Patients must be queried about any general side effects and the side effects that accompany their specific therapy. Querying about side effects is perhaps the most straightforward, simple, and efficient intervention that could be provided to improve epilepsy care and patient outcomes.</td>
</tr>
</tbody>
</table>

*Intervention: Discussion about significance of side effect symptom and consideration of adjustment in anti-seizure therapy or medication dose or providing alleviating treatment.
Measure 2: Anti-epileptic drug side effect interventions was predicted to increase by 5% and a 23.4% improvement was demonstrated. Many practices targeted this measure for their QI efforts by integrating patient and provider education as well as documentation templates into practice workflows.
### #3: PERSONALIZED EPILEPSY SAFETY ISSUE AND EDUCATION PROVIDED

<table>
<thead>
<tr>
<th>Measure Description</th>
<th>Percent of all patients with a diagnosis of epilepsy, or their caregivers, who were provided with personalized safety issue and epilepsy education at least once annually.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Numerator</strong></td>
<td>Patients or their caregivers were provided personalized epilepsy safety issue* and education and resources** at least once a year.</td>
</tr>
<tr>
<td><strong>Denominator</strong></td>
<td>All visits for patients with a diagnosis of epilepsy.</td>
</tr>
<tr>
<td><strong>Denominator Exceptions</strong></td>
<td>Caregiver is unavailable for a patient who is non-communicative or has an intellectual disability.</td>
</tr>
<tr>
<td><strong>Rationale for Measure</strong></td>
<td>People with epilepsy are at a greater risk for injury and accidents. Providing patients or caregivers with personalized epilepsy safety issue information and education will increase personal safety while promoting self-management and improving quality of life.</td>
</tr>
</tbody>
</table>

*Safety issues to be addressed should be appropriate to the patient’s age, seizure type(s) and frequency, occupation, and leisure activities. (eg, injury prevention, falls, burns, appropriate driving restrictions (including state specific restrictions), or bathing).

**Epilepsy education topics to be addressed should be appropriate to the patient’s age, seizure type(s) and frequency. (eg, diagnosis and treatment options, medication and side effects, treatment specific surveillance laboratory testing, seizure types, triggers and seizure control, management and self-care, psychological issues, social security benefits and social services, insurance issues, education and healthcare at school, employment and independent living for adults, importance of disclosing epilepsy at work, sudden death in epilepsy (SUDEP), status epilepticus, maintaining a healthy life style, driving education, leisure and social issues (including recreational drugs, alcohol, sexual activity and dysfunction, and sleep deprivation), family planning, pregnancy and parenting concerns, and available resources including voluntary organizations and patient support associations.
Measure 3: Safety education was predicted to increase by 30% and a statistically significant improvement of 41.6% was demonstrated. Most practices focused on this measure for PDSA cycles and QI efforts by integrating educational resources and documentation templates to guide improvement.
## #4: Screening for Psychiatric or Behavioral Health Disorders

<table>
<thead>
<tr>
<th>Measure Description</th>
<th>Percent of all visits for patients with a diagnosis of epilepsy where the patient was screened for psychiatric or behavioral disorders.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>Patient visits where patient was screened* for psychiatric or behavioral health disorders.**</td>
</tr>
<tr>
<td>Denominator</td>
<td>All visits for patients with a diagnosis of epilepsy.</td>
</tr>
<tr>
<td>Denominator Exceptions</td>
<td>Caregiver is unavailable for a patient who is non-communicative or has an intellectual disability.</td>
</tr>
<tr>
<td></td>
<td>Patient has an existing diagnosis of psychiatric disorder and is being actively treated.</td>
</tr>
<tr>
<td></td>
<td>Patient declines screening.</td>
</tr>
<tr>
<td>Rationale for Measure</td>
<td>The prevalence of psychiatric and behavioral health comorbidities in patients with epilepsy is well documented and the relationship between epilepsy and psychiatric and behavioral health disorders is complex. Cognitive dysfunction is also a major concern for all people with epilepsy. A gap remains between early detection, treatment, and prevention of psychiatric, cognitive, and social comorbidities in epilepsy. Patients with epilepsy report dissatisfaction with life overall and perceive limitations in their social and emotional support.</td>
</tr>
</tbody>
</table>

*Screened: Questioning by the individual provider to identify areas of concern, may include standardized testing.

**Psychiatric or behavioral disorders may include, but are not limited to anxiety, depression, suicidality, mood disorder, attention deficit hyperactive disorder, cognitive dysfunction, or other neurobehavioral disorders.
**Measure 4:** Screening for behavioral and mental health was predicted to increase by 5% and a 32.2% improvement was identified, which is statistically significant. Many practices targeted this measure for their QI efforts by incorporating validated scales and documentation templates into practice workflow.
#5: COUNSELING FOR WOMEN OF CHILDBEARING POTENTIAL WITH EPILEPSY (OPTIONAL MEASURE)

<table>
<thead>
<tr>
<th>Measure Description</th>
<th>All female patients of childbearing potential (12-44 years old) diagnosed with epilepsy who were counseled or referred for counseling for how epilepsy and its treatment may affect contraception OR pregnancy at least once a year.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>Female patients or caregivers counseled* at least once a year about how epilepsy and its treatment may affect contraception OR pregnancy.</td>
</tr>
<tr>
<td>Denominator</td>
<td>All females of childbearing potential (12-44 years old) with a diagnosis of epilepsy. Excluded: patients diagnosed with menopause or surgically sterile.</td>
</tr>
<tr>
<td>Denominator Exceptions</td>
<td>Patient has a diagnosis of neurodevelopmental disorder, encephalopathy, hydrocephalus, brain injury, or cerebral palsy. Patient has a diagnosis of severe cognitive impairment or severe intellectual disability.</td>
</tr>
<tr>
<td>Rationale for Measure</td>
<td>Epilepsy is associated with reduced fertility, increased pregnancy risks, and risks for malformations in the infant. Treatment of seizures with anti-seizure medications may alter hormone levels, render oral contraceptives less effective and may interfere with embryonic and fetal development. Certain anti-seizure medications may have specific malformation risks. Folic acid supplementation, monotherapy for epilepsy, using lower doses of medication when possible, and proper obstetrical, prenatal and pre-pregnancy care all should be discussed with the patient, so they understand the risks involved and how to mitigate these risks.</td>
</tr>
</tbody>
</table>

*Counseling should include a discussion about folic acid supplementation, contraception, potential anti-seizure medications effect(s) on pregnancy, safe pregnancies, and breastfeeding.
Measure 5: Counseling women of childbearing was an optional measure predicted to increase by 5% and a decline of 7.8% was identified. Most practices elected not to collect data on this measure and there was also inconsistency in who elected to measure, making an analysis extremely difficult. It was also not a measure that any practice chose to work on for their QI efforts.
#6: REFERRAL TO COMPREHENSIVE EPILEPSY CENTER

<table>
<thead>
<tr>
<th>Measure Description</th>
<th>Percent of all patients with a diagnosis of treatment resistant (intractable) epilepsy who were referred for consultation to a comprehensive epilepsy center* for additional management of epilepsy.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>Patients who were referred for consultation to a comprehensive epilepsy center* for additional management of epilepsy.</td>
</tr>
<tr>
<td>Denominator</td>
<td>All patients with a diagnosis of treatment resistant (intractable) epilepsy.**</td>
</tr>
</tbody>
</table>
| Denominator Exceptions | Patient is already being seen at a comprehensive epilepsy care center.  
Patient has been evaluated within the past 2 years.  
Patient declined referral.  
Patient has non-disabling seizures. Non-disabling is defined by the treating provider and patient.                                                                 |
| Rationale for Measure | Referral to a comprehensive epilepsy center is needed to ensure patients are properly evaluated for epilepsy surgery, have access to ancillary epilepsy resources, and for the use of alternative epilepsy therapies as these treatments are efficacious and may not be provided in general practice. Epilepsy resective surgery is a potential curative procedure. The superiority of resective epilepsy surgery for control of treatment resistant (intractable) epilepsy over standard medical care has been demonstrated through randomized controlled trials.  
Further, alternative treatments for epilepsy, such as neurostimulation, dietary therapy, felbamate and vigabatrin, are prescribed almost exclusively at epilepsy centers as they have been restricted to patients with treatment resistant (intractable) epilepsy. |
epilepsy for whom the benefit outweighs the risk for these treatments. Since a surgical evaluation and other available resources for treatment resistant (intractable) epilepsy can only be performed at a comprehensive epilepsy center, patients with treatment resistant (intractable) epilepsy should be referred for management. These patients will need periodic re-evaluation at a comprehensive epilepsy center to determine whether a new intervention is needed, such as new epilepsy surgery techniques, devices, or an alternative anti-seizure medication.

*Comprehensive Epilepsy Care Center: Epilepsy centers that provide comprehensive diagnostic and treatment modalities and access to multidisciplinary teams to address comorbidities that are common in epilepsy. The National Association of Epilepsy Centers has provided details of the essential services, personnel, and facilities at comprehensive epilepsy centers. In general, comprehensive centers will provide diagnostic evaluation including inpatient video electroencephalogram (EEG) monitoring, epilepsy surgery evaluation, access to epilepsy surgery, and staff to address psychiatric and psychosocial issues.

**Treatment resistant (intractable) epilepsy is defined as “failure of adequate trials of two tolerated, appropriately chosen and used antiepileptic drug schedules to achieve sustained seizure freedom.”"
Measure 6: Referral to a tertiary center was predicted to increase by 5% and a 26.7% improvement was identified. Practices targeted this measure briefly after data cycle 3 by adding documentation of the referral into the electronic health record which facilitated the biggest gains.
#7: DOCUMENTATION OF AN EPILEPSY TRANSITION PLAN

<table>
<thead>
<tr>
<th>Measure Description</th>
<th>Percentage of patients who had a neurological transition plan of care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Numerator</td>
<td>Pediatric neurology patients with chronic ongoing neurological condition &gt; 13 years of age that have had a documented neurological transition plan of care* initiated and updated annually with copy given to patient and/or caregiver *</td>
</tr>
<tr>
<td>Denominator</td>
<td>Pediatric neurology patients with chronic ongoing neurological conditions &gt; 13 years of age</td>
</tr>
</tbody>
</table>
| Denominator Exceptions | A patient does not need continued care  
Patient/caregiver refuses to see the adult provider or participate in the transition planning |
| Rationale for Measure | Adolescent and young adult neurology patients will be properly transitioned to adult neurology care. No gap will occur. Rate of proper completion will occur with improved patient and caregiver satisfaction with transition, stability or improvement of neurological condition, decrease emergency utilization and improved quality of life. |

*Neurological transition plan of care must include ALL of the following, but not limited to:

- Medical plan (pertinent medical and surgical history related to neurological condition, current and past neurological medications with adverse effects, previous and future needed testing)
- Discussion of existing office transition policy with expected year of transition given to patient and caregiver
- Patient self-management skills assessment
- Transition readiness assessment
- Patient current and expected legal competency
- Patient plan for employment, school, vocation, placement (for profound intellectual disability patients), etc.
- Emergency plans (medical power of attorney, living will, DNR, plans for guardianship for patients with profound intellectual disability)
- Name of provider providing or accepting care of neurological condition (at time of transition).
**Measure 7:** Documentation of a transition plan was predicted to increase by 20% and a 45.3% improvement was identified, which is statistically significant. It was identified that there was a need for clarification of the AAN measure which was improved by introducing Got Transition resources.
The AAP Epilepsy and Comorbidities ECHO evaluation included 4 components – 1) participation data (eg # of unique participants, average participation per session), 2) post-session CME surveys to assess participant satisfaction with presentation and session content, 3) a post-program survey to assess participant change in knowledge and self-efficacy regarding care for CYE before and after ECHO participation, and 4) focus groups to obtain in-depth information regarding participants’ ECHO experience as well as program impact and outcomes at the practice and system levels. Taken together, findings from these sources suggest positive outcomes for individual learners and their practice settings as a result of CYE ECHO.

Participants endorsed the AAP Epilepsy and Comorbidities ECHO as a valuable use of time and a learning modality that increased professional satisfaction as well as interest in and understanding of the subject matter. Among those who completed a post-program survey, we found statistically significant differences in important areas of knowledge and self-efficacy regarding care for CYE after ECHO participation.

Through focus groups and surveys, participants described the ways in which CYE ECHO drove practice-based changes in care processes, workflows and systems of care. An assessment of practice improvements in key QI measures including safety education, behavioral health screening, and transition corroborated reports of practice-level changes over the course of CYE ECHO. Below are a few participant quotes from the ECHO to illustrate outcomes and impact of the project:

“I really appreciated the medication lecture and the safety lecture. The safety lecture – I don’t think that prior to this we had done a good job...we often thought of the safety issues with epilepsy to go along with what’s developmentally appropriate, but we had a child die from an unsafe sleep environment. They were in a non-hospital bed and they probably had a seizure and were smothered and so that was a bell. That was one lecture that really stood out to me that helped improve our practice. We almost always talk about sleep safety in our neurodevelopmentally delayed [patients] with epilepsy now. The lecture provided new information and it made us realize that we hadn’t been covering all the bases with safety.”
“We really focused on the safety piece – that measure has probably had the greatest impact. It’s so much more at the forefront now for me to help families go over that, especially for a child with seizures, it was really impactful. [Moderator: What’s changed? What do you do differently now?] Really emphasizing that they’re not taking baths by themselves, having things set up, I mean when you’re seeing 30-40 kids in a day and they’re not in there for a well visit and they’re not in there for seizure, it’s not at my forefront – it’s like okay ‘here’s my seizure kid he’s got a virus, out the door they go’ but if I can even just verbally highlight a couple safety things like ‘How is that going?’ and ‘How are we doing?’ and ‘Child is about to start driving, have you thought about how to approach that?’ It’s just much more to my forefront now.”

“I’m thinking about side effects. I’m much better about asking about medication side effects. I could just kind of gloss over it and say ‘Well, how’s it going? Do you notice anything? You look great to me!’ But thinking more about, ‘Are you having dry mouth? Are you having more sedation? Are you having…’ and reporting that back to the neurologist and trying to figure out if this is the best drug for them? I’m much more sensitive to that. Before I was just ‘Are you getting your medications filled and are you taking them and are you getting adherence?’ I’m much more sensitive to that. Kari helped set up how to get it in the EMR so that we can document side effects because you worry if you start talking about that you’re going to give people a suggestion about of how.”
LESSONS LEARNED

<table>
<thead>
<tr>
<th>Timeline</th>
<th>• Develop a program that is long enough to see improvement but not too long to be a barrier for participation. Ex: 6-month QI ECHO program.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Site Champion</td>
<td>• Identify a site champion at each practice to motivate staff to engage in the program and help drive sustainable practice change.</td>
</tr>
<tr>
<td>Faculty Onboarding and Engagement</td>
<td>• Involve faculty during all phases of the project (planning, implementation and evaluation) to seek ongoing feedback.</td>
</tr>
</tbody>
</table>
| QI Education | • Provide education in fundamental QI principles and tools that are needed to improve processes in practice.  
• Provide clarity on program measures.  
• Review data collection tool to ensure it meets the unique needs of the practices. |
| AIM Statement | • Facilitate adoption of a clear, focused, and appropriate goal. A clear aim statement is essential for communication to flow smoothly between all stakeholders. |
RESOURCES

Epilepsy & Comorbidities

- **American Academy of Neurology**
  - 2014 Epilepsy Quality Measurement Set
- **American Academy of Pediatrics**
  - Bright Futures
    - Developmental, Behavioral, Psychosocial, Screening, and Assessment Forms
  - Healthychildren.org
    - Seizure Medications for Children and Teens
  - National Coordinating Center for Epilepsy
    - Epilepsy Compendium
  - Clinical Reports & Policy Statements
    - Rescue Medicine for Epilepsy in Education Settings
    - AAP Position: Medical Marijuana
- **American Epilepsy Society**
  - Clinical resources
  - Summary of Antiepileptic Drugs Available in the United States of America
- **American Psychological Association**
  - Society of Pediatric Psychology
- **Child Neurology Foundation**
- **Child Neurology Society**
- **Epilepsy Foundation**
- **Managing Epilepsy Well Network**

Family & Community Engagement

- **American Academy of Pediatrics**
  - Family Engagement QI Implementation Guide
  - Healthychildren.org
- **Child Neurology Foundation**
  - Seizure Action Plans
- **Family Voices**
  - Network of Family Led Organizations
  - Overview of Family Voices and Affiliated Organizations
Quality Improvement

- **American Academy of Neurology**
  - EHR Templates
- **American Academy of Pediatrics**
  - Epilepsy Checklist for Providers
  - Process Improvement Workflow Template
  - Quality Improvement in Pediatric Epilepsy
  - Quality Improvement in the Pediatric Practice
  - Quality Improvement Resources
- **Institute for Healthcare Improvement**
  - Cause and Effect Diagram and Tools
  - Flowchart Diagram and Tools
  - Quality Improvement Essential Toolkit
  - Seven Popular Improvement Tools
  - Use Daily Huddles to Make Improvement Stick
    - Many organizations use huddles during care transitions. But the daily huddle can do much more. These brief stand-up meetings give teams a way to actively manage quality and safety.
- **JAMA Network**
  - Clinical Utility of Reinterpreting Previously Reported Genomic Epilepsy Test Results for Pediatric Patients
- **National Institute for Children’s Health Quality**
  - QI Tips: A Formula for Developing a Great Aim Statement
- **The Lancet Global Health**
  - High-quality health systems in the Sustainable Development
- **The National Academies Press**
  - Crossing the Global Quality Chasm: Improving Health Care Worldwide
  - Recommendations: Crossing the Global Quality Chasm *Improving Health Care Worldwide*

**Referrals**

- **National Association of Epilepsy Centers**
- **Epilepsy Foundation**
  - The Comprehensive Epilepsy Center
Transition

- **American Academy of Pediatrics**
  - Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home
- **Got Transition**
  - NEW TOOLKIT: Incorporating Health Care Transition Services into Preventive Care for Adolescents and Young Adults ([English](#), [Spanish](#))
  - 2018 Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care

Webinars

- **AAP CYE Stakeholder Forum Webinar Series**
  - Seizures in Children and Youth: Overview for the Primary Care Provider
  - Testing and Diagnosis for Seizures in Children and Youth
  - Common Comorbidities in Children and Youth with Seizures (Part 1)
- **Measure What Matters: Advancing Multidisciplinary Care Coordination in Primary Care Settings.** Faculty slides as well as recordings for both webinars are [available here](#).
**QI TEMPLATES**

**WORKFLOW PROCESS EXAMPLES**

**Process Map**

**Process Name:** eScripting Medications and Pharmacy questions

**Date Created:** 5.31.2018

**Start Step:** Medication ordered in EPIC → eScripted to Pharmacy

**End Step:** Patient receives appropriate medication

---

1. **Patient seen on ECO/PH needs a script which is ordered in EPIC and abbreviated to the patient's preferred pharmacy.**

2. **Pharmacy receives Rx, are there questions/concerns with order?**
   - **No:** Contact Dr. Turner directly at [phone number] (please keep confidential)
   - **Yes:**
     - **Pharmacist will look on eScript for contact number for provider.**
     - **Provider contact number available and accurate?**
       - **Yes:** Questions/concerns clarified and refilled if appropriate
       - **No:**
         - **Provider not on EPIC: does not see urgent message. Can use CMS or other technology to get this message to provider immediately?**
   - **No provider # or inaccurate # on script.**

---

**GOAL:** Safe, efficient, effective process for timely medication order writing and filling.
Process Map

Process Name: Epilepsy Seizure Frequency Inquiry Call- Appt. Triage

Date Created: Start Step: Create call list End Step: Triage determination

CLARIFYING QUESTIONS
Who creates this list?
How is it created (SOP)?
How often will it be created?
Who contacts patient? Only be call?— sms via patient portal?
How many outreach max?
Is the call scripted and if yes-script developed?
Documentation of call?
Go live date?
POSA by provider? How long and what are your expected outcomes for measures and what barriers do you anticipate?

SMART GOALS
Try using the SMART acronym to make sure your goals are clear and reachable!
- Specific (simple, sensible, significant).
- Measurable (meaningful).
- Achievable (agreed upon, attainable).
- Relevant (reasonable, realistic, results-based).
- Time bound (time-boxed, time limited, time-sensitive).

GOAL OF CALL
a) assess any parental concerns
b) review any side effects that patients had on medications
c) review safety parameters and any difficulty in maintaining them
d) timely follow-up with specialist
Purpose: Optional documentation elements to include for a provider during an office-visit.

Patient Name:                                                                                                  Primary Care Provider:
D.O.B.                                                                                                           Sex:                                                                                       MRN:
Epilepsy Diagnosis:

Testing/ Imaging:

<table>
<thead>
<tr>
<th>Imaging</th>
<th>Last Date Done</th>
<th>Due Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>MRI</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EEG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Genetic Testing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pertinent Labs:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AED Levels</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Others?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Medications:

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dose</th>
<th>Last Refill</th>
<th>Known Side Effects?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
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<td></td>
</tr>
</tbody>
</table>

Immunizations: Up to Date/ Catch up Schedule
Due for ______________________________

Development:
Mental Health Screening? Yes/ No Last done? Screening tool_____________________
Referral Yes/ No

Family History:
ROS: Pertinent ROS______________________________________________________________
Seizures are static, worsening or improving? ________________________________
**Seizure Frequency:**
- More than 10 per day on most days
- 4 or more days in a typical week
- 3 or fewer days in a typical week
- 1 to 3 per month in most months
- Less than once per year
- Uncertain

**Seizure Observation:**
- Duration
- Triggers
- Awareness Level
- Movements
- Speech
- Post seizure
- Uncertain

**Vital Signs:**

**Physical Exam:**

**General**

**Head**

**Cranial Nerves**
- CN I (olfactory)
- CN II (optic)
- CN III, IV, and VI (oculomotor, trochlear, abducens)
- CN V (trigeminal)
- CN VII (facial nerve)
- CN VIII (auditory)
- CN IX, X (glossopharyngeal, vagus)
- CN XI (spinal accessory)
- CN XII (hypoglossal)

**Motor**

**Cerebellar Functioning/ Sensory**

**Reflexes**
- jaw jerk (CN V)
- biceps (C5-6)
triceps (C6-8)
brachioradialis (C5-6),
patellar (L2-4)
ankle (S1-2).

**Posture** (resting)/**Tone** (passive/active)

**Assessment/ Plan:**

**Follow Up:** In _ weeks/months

**Patient Education:**

1. **Safety: (Check all Discussed)**
   - Bicycle Safety
   - Sports Safety
   - Bathing
   - Swimming
   - Safety-proofing the home
   - Driving safety and regulations
   - Lifestyle (including recreational drugs, alcohol, sexuality)
   - Sleep Hygiene
   - Female health issues
   - Need for the development of a Seizure Action Plan
   - Known seizure triggers
   - Other________________

2. **Seizure Action Plan:**

3. **Transitions of Care:** (13 years and older)

   **Referrals Made To:**
   - ☐ Psychology
   - ☐ Genetics
   - ☐ PT/OT

   **Resources:**
   - ☐ Epilepsy Foundation for assistance
   - ☐ Child Neurology Foundation
   - ☐ Healthy Children.org
## MEDICATION SIDE EFFECTS TEMPLATE FOR PATIENTS

<table>
<thead>
<tr>
<th>Epilepsy- Medication Management</th>
<th>Please circle the side effect below if your child is having any of the following side effects.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MEDICATION</strong>&lt;br&gt;Trade/ Generic Name</td>
<td><strong>SIDE EFFECTS</strong>&lt;br&gt;<strong>COMMENTS</strong>-</td>
</tr>
<tr>
<td>Trileptal / Oxcarbazepine</td>
<td>Blurry vision / Double vision / Dizzy / Drowsy / Feeling tired&lt;br&gt;Headache / Trouble concentrating / Trouble sleeping&lt;br&gt;Stomach upset / Nausea / Vomiting / Diarrhea / Constipation&lt;br&gt;Problems with Speech / Balance / Walking / Tremor</td>
</tr>
<tr>
<td>Topamax / Topiramate</td>
<td>Change in Vision / Problem with Vision / Dizzy / Easy bruising</td>
</tr>
<tr>
<td>Drug</td>
<td>Side Effects</td>
</tr>
<tr>
<td>--------</td>
<td>------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Lamictal/Lamotrigine | Double vision / Blurry Vision / Dizzy / Rash  
|         | Fatigue / Feeling tired / Headache / Difficulty sleeping  
|         | Unsteadiness / Nausea / Vomiting  |
| Keppra/Levetiracetam | Dizzy / Problem with Coordination / Fatigue / Feeling tired  
|         | Aggression / Depression / Irritability / Rash / Easy bruising  |
| Onfi/Clobazam | Fatigue / Feeling sleepy / Difficulty sleeping / Rash  
|         | Weight gain / Constipation / Vomiting / Drooling  
|         | Fever / Cold-like symptoms- (runny nose, stuffy nose, headache)  
|         | Problems with Walking / Balance / Problem with Coordination  
|         | Irritable / Depression / Agitation  |

*Adapted from AAP Epilepsy and Comorbidity ECHO presentation Session 5 (8/29/2018) Drs. Brown and Joshi

** For additional information please see Summary of Antiepileptic Drugs by the American Epilepsy Society (revised July 2018) http://epilepsycurrents.org/doi/pdf/10.5698/1535-7597.18.4s1.1?code=amep-site
| **Medication Name** | Keppra  
also called levetiracetam |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is it for?</strong></td>
<td>This medicine is used to treat seizure disorders and to decrease the number of seizures your child may have.</td>
</tr>
</tbody>
</table>
| **How to take.** | Keppra comes in tablets and certain pharmacies can make into liquid.  
Can be taken with or without food. Food may decrease an upset stomach.  
Give this medication at the same time each day, picking a time that is easy to remember so you do not miss a dose.  
Do NOT increase or decrease a dose unless your physician/ nurse practitioner/ or physician assistant tells you.  
Do NOT stop taking without talking to your physician/ nurse practitioner/ or physician assistant first. Sudden stopping may cause seizures to return. |
| **Possible Side Effects.** | Your child may have some of these side effects while they take levetiracetam. Check with your child's doctor if your child continues to have any of these side effects and they do not go away, or they bother your child:  
feeling sleepy  
weakness  
dizziness  
Call your child's doctor during office hours if your child has any of these side effects:  
easy bruising  
clumsiness or unsteadiness  
loss of memory  
changes in mood (more angry, sad, or nervous)  
increase in seizures |
<table>
<thead>
<tr>
<th><strong>Most of the following side effects are not common, but they may be a sign of a serious problem. Call your child's doctor right away or take your child to Emergency if your child has any of these side effects:</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>swelling of the face, lips, or tongue</td>
</tr>
<tr>
<td>wheezing or difficulty breathing</td>
</tr>
<tr>
<td>rash or hives (red raised spots on the skin)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Safety</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not stop giving your child levetiracetam suddenly</td>
</tr>
<tr>
<td>Levetiracetam may make your child dizzy, drowsy, or less alert than normal, especially at the beginning of therapy. Have your child avoid tasks or activities that require alertness until you see how this medicine affects them. Your child’s teacher should also know that they are taking medication with these effects.</td>
</tr>
<tr>
<td>Girls taking the birth control pill should report irregular periods or increased spotting to their doctor.</td>
</tr>
<tr>
<td>There are some medicines that should not be taken together with levetiracetam. It is important that you tell your doctor and pharmacist if your child takes any other medications (prescription, over the counter, or herbal). Some medicines cause drowsiness and the dose of these medications may have to be adjusted when taken with levetiracetam. Examples include certain cold medicines, sleeping medicines, and other medications used to treat seizures.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Other Information</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Do not share your child’s medication with others. Do not give anyone else’s medication to your child.</td>
</tr>
<tr>
<td>Make sure you always have enough levetiracetam to last through the weekends, holidays and vacations. Call to get your refill at least 3-5 days before your child runs out.</td>
</tr>
<tr>
<td>Keep levetiracetam at room temperature in dry place and avoid sunlight.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Questions?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Please contact your healthcare provider at_________________________ or your local pharmacist</td>
</tr>
</tbody>
</table>
## Epilepsy - Medication Management

### First Line Treatment of Common Childhood Epilepsies
- Focal epilepsy: oxcarbazepine, levetiracetam
- Childhood Absence Epilepsy: ethosuximide
- Juvenile Myoclonic Epilepsy: valproate, levetiracetam
- Lennox Gastaut Syndrome: valproate
- Infantile spasms: steroids (ACTH, prednisolone), vigabatrin (drug of choice in tuberous sclerosis)

### Abortive Medications

<table>
<thead>
<tr>
<th>Medication</th>
<th>Commercially available</th>
<th>Conditionally available</th>
<th>Research formulations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diazepam</td>
<td>Rectal gel</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clonazepam</td>
<td>Wafer, disintegrating</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>tablet [ODT]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Midazolam</td>
<td>Intransal (needs special atomizer devise to make mist); buccal (may be available at compounding pharmacy)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Dosing:

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dosage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rectal Diazepam Gel</td>
<td>&lt;2 years: off-label use in infants &gt; 6 months</td>
</tr>
<tr>
<td></td>
<td>2-5 years: 0.5 mg/kg</td>
</tr>
<tr>
<td></td>
<td>6-11 years: 0.3 mg/kg</td>
</tr>
<tr>
<td></td>
<td>&gt; 12 years: 0.2 mg/kg</td>
</tr>
<tr>
<td>Nasal/buccal Midazolam</td>
<td>13 - 40 kg: 5 mg once</td>
</tr>
<tr>
<td></td>
<td>&gt;40 kg: 10 mg once</td>
</tr>
<tr>
<td>Oral Clonazepam</td>
<td>&lt; 40 kg: 1 mg</td>
</tr>
<tr>
<td></td>
<td>&gt; 40 kg: 2 mg</td>
</tr>
</tbody>
</table>

Rectal diazepam is FDA approved only for cluster seizures but used routinely for out-of-hospital treatment of seizures > 5 minutes.

Best rescue medicine chosen in accordance with patient/caregiver preference.
<table>
<thead>
<tr>
<th>Medication</th>
<th>Side Effects</th>
<th>Comments</th>
</tr>
</thead>
</table>
| Oxcarbazepine | **Main Side Effects:**  
Blurry vision  
Dizziness / incoordination/ Fatigue  
Stomach upset  
Hyponatremia | First line for focal seizures  
Structurally similar to carbamazepine, but better tolerated with less hepatic induction and fewer drug interactions  
May stabilize mood |
| Valproate    | **Common side effects:**  
- weight gain, hair loss, tremor  
- blood or liver injury, pancreatitis  
- Menstrual irregularities, PCOS  
- Higher risk of fetal neural tube defects  
- AVOID < 2 years and with suspected mitochondrial (POLG1) disorder | Broad spectrum, including generalized  
Mood stabilizer, effective for headaches |
| Lamotrigine  | **Main Side Effects:**  
- Rash, including Steven Johnson syndrome  
- Fatigue  
- Unsteadiness  
- Rarely HLH syndrome | Broad spectrum against seizures: used in absence epilepsy, JME, LGS, focal epilepsies  
Can be taken BID; available as extended release QD  
Can stabilize mood  
**AVOID** in Sodium channel defects (Dravet syndrome); can make epilepsy worse |
| Topiramate   | **Common side effects:**  
- Slow / Fuzzy thinking/Speech difficulties  
- Kidney stones in ~ 2%  
- Weight loss/anorexia  
- Anhidrosis  
**Rare side effects:**  
- Glaucma  
- Psychiatric problems | Broad spectrum action  
Can also help migraines, Tourette syndrome |
| Levetiracetam| **Main Side Effects**  
Dizziness/ incoordination  
Fatigue  
Rare psychiatric effects: aggression, irritability | Broad spectrum  
Commonly used for treating Juvenile Myoclonic Epilepsy (JME)  
Available as IV  
Few drug interactions |
| Zonisamide   | **Main Side Effects:**  
- Slow / Fuzzy thinking  
- Kidney stones in ~ 2%  
- Anorexia  
- Anhydrosis  
- Rare psychiatric problems | Broad spectrum action  
Good for myoclonic seizures  
Can be once a day  
Structurally related to sulfa drugs: need to check for sulfa allergy |
| Ethosuximide | **Main Side Effects**  
Dizziness / unsteadiness  
GI upset  
Sedation  
Can cause mild lowering of WBC counts | First line for absence epilepsy  
Inexpensive |
REFERENCES

1. Institute of Medicine (US) Committee on the Public Health Dimensions of the Epilepsies; England MJ, Liverman CT, Schultz AM, et al., editors. Epilepsy Across the Spectrum: Promoting Health and


APPENDIX A - CASE PRESENTATION FORM

AAP Epilepsy and Comorbidities
ECHO
Case Presentation Form

PLEASE NOTE that Project ECHO® case consultations do not create or otherwise establish a provider-patient relationship between any hub faculty and any patient whose case is being presented in a Project ECHO® setting.

PRACTICE INFORMATION

Case Number (For Office Staff Only):
Practice Name:
Date of Team Meeting:

List the full names of all physicians seeking MOC Part IV credit, who actively participated in the team meeting for this data cycle: Please note, physicians seeking MOC Part IV credit MUST have their full names list below, clearly written.

PATIENT INFORMATION

Gender: □ Male □ Female Age: ______
Height: ______ cm Weight: ______ kg

What is your main question about this case?

Summarize the case in 4 points

1.
2.
3.
4.
Please provide additional details regarding the case by completing the remaining sections of this form.

**DETAILS OF SEIZURE**

Approx. date of onset _______ Duration _______ Frequency _______
When do seizures occur? □ Wake □ Sleep □ Both □ Random
Do seizures occur in clusters? □ Yes □ No
Are there provoking factors? □ Fever □ Sleep Deprivation □ Flashing Lights □ Menses
□ Other (please explain)
Have the episodes been verified by EEG to be seizures? □ Yes □ No □ Video EEG □ Regular EEG

**Imaging:**
CT: □ Yes □ No Year Performed: _______ Result: _______
MRI: □ Yes □ No Year Performed: _______ Result: _______

**MEDICAL HISTORY**

**PAST MEDICAL HISTORY**
Pre/peri/postnatal complications:
Hospitalizations:
Chronic medical/psych conditions:
Surgery:
Injuries:

**PERTINENT FAMILY MEDICAL HISTORY:**
□ Febrile Seizures □ Nonfebrile Seizures □ Neurological Disorders □ Sudden Death/Cardiac
□ Unknown

**SOCIAL HISTORY:**
With whom does the patient live? __________
Substance Use: □ Yes □ No __________
Does the patient exercise regularly? □ Yes □ No □ Unknown

**REVIEW OF SYSTEMS:**
Examination findings
General Examination:
Neurologic Examination:
Alertness, ability to communicate and cooperate:

**LABORATORY TESTING** (you may attach de-identified copies of reports)
Routine:
Metabolic tests:
Genetic tests:

**MEDICATION HISTORY**
Current daily medication(s):
Prior seizure medication(s):
Recent anticonvulsant levels:
Side effects of Seizure Medication(s):

COUNSELING
Has surgical referral been considered? □ Yes □ No □ Unknown
Has counseling about epilepsy safety issues been offered? □ Yes □ No □ Unknown
If yes, please describe the topic of counseling: □ Driving □ Water Safety □ Other (Please describe)
Has reproductive counseling been offered to females ages 13-24? □ Yes □ No □ Unknown

GROWTH AND DEVELOPMENT
□ Normal □ Mild Delay □ Moderate Delay □ Severe Delay
Cognitive Issues: □ Attention □ Processing Speed □ Memory □ Executive Processing □ Intellectually Impaired

PSYCHIATRIC DIAGNOSES
Has the patient been screened for psychosocial comorbidities? □ Yes □ No □ Unknown
If Yes, what screening tool was used? ___________________________
If screening was positive, was referral made? □ Yes □ No □ Unknown
Has the patient been diagnosed with any of the following?
□ ADHD disorders □ Learning □ Communication □ Mood □ Behavioral □ Bipolar Disorder
□ Depression □ Anxiety □ Suicide Ideation □ Suicide Attempt □ Prior Institutionalization
□ Schizophrenia □ Other (if known): ________
If YES to depression and/or anxiety, please describe the following:
Changes in □ Sleep □ Appetite □ Recreation □ Energy Level □ Other (Please describe)

SCHOOL HEALTH
Grade in school: __________________________
Does the patient have an IEP (Individualized Education Plan)? □ Yes □ No □ Unknown
Does the patient have a 504 plan? □ Yes □ No □ Unknown
Does the patient have a seizure action plan in place at school? □ Yes □ No □ Unknown
| APPENDIX B- PDSA FORM |

| **Model for Improvement**  
| **PDSA Planning Worksheet** |

| **Today’s Date:** |

| **PLAN** |
| Objectives for this cycle: |
| Questions: |
| Predictions: |
| Plan for change or test: who, what, when, where: |
| Plan for collection of data: who, what, when, where: |

| **DO** |
| Carry out the change or test. Collect data and begin analysis. Describe observations, problems encountered, and special circumstances. |

| **STUDY** |
| Complete analysis of data. Summarize what was learned. |

| **ACT** |
| Are we ready to make a change? Plan for the next cycle. |
## APPENDIX C - DATA COLLECTION TOOL

1. Please identify the age of the patient at the time of the office visit:
   - Younger than 1 Year
   - 1 Year
   - 2 Years
   - 3 Years
   - 4 Years
   - 5 Years
   - 6 Years
   - 7 Years
   - 8 Years
   - 9 Years
   - 10 Years
   - 11 Years
   - 12 Years
   - 13 Years
   - 14 Years
   - 15 Years
   - 16 Years
   - 17 Years
   - 18 Years
   - 19 Years
   - 20 Years
   - 21 Years
   - 22 Years
   - 23 Years
   - 24 Years

### Seizure Frequency

2. Is there documentation in the patient’s chart of seizure frequency?
   - Yes
   - No

   2A. What was the seizure frequency documented in the record?
   - More than 10 per day on most days
   - 4 days per week with 2 or more seizures, in a typical week
   - 4 or more days in a typical week
   - 3 or fewer days in a typical week
   - 1 to 3 per month in most months
   - 10 or fewer in the past 12 months
   - Less than once per year
   - Uncertain

3. Was there documentation of an intervention to decrease seizure frequency?
   - Yes
   - No

   3A. What was the intervention? (Check all that apply)
   - A change in current medication dosage
   - A new medication was prescribed for the seizures
   - A new medication to help with the side effects was prescribed
   - A current medication was discontinued
   - Referral to a child neurologist or an epilepsy specialist
   - Telephone consultation with specialist
   - Discuss adherence to medications
   - Other
**Medication Management**

4. Is there documentation in the patient’s chart of discussion for side effects of anti-seizure therapy?
   - ○ Yes  ○ No

5. Is there documentation that there was discussion of a safety issue?
   - ○ Yes  ○ No

   5A. What was the safety issue discussed? (Check all that apply)
   - □ Bicycle Safety
   - □ Sports Safety
   - □ Bathing
   - □ Swimming
   - □ Safety-proofing the home
   - □ Driving safety and regulations
   - □ Lifestyle (including recreational drugs, alcohol, sexuality)
   - □ Sleep Hygiene
   - □ Female health issues
   - □ Need for the development of a Seizure Action Plan
   - □ Known seizure triggers
   - □ Other

**Psychiatric and Behavioral Screening**

6. Is there documentation in the patient’s chart that they were screened for psychiatric or behavioral health disorders (such as anxiety, depression, mood disorder, ADD/ADHD, cognitive dysfunction or neurobehavioral disorders) using a validated screening tool within the last 12 months?
   - ○ Yes  ○ No  ○ N/A

   6A. What was the screening tool used?

   6B. If the screening tool indicated that additional medical care was appropriate, is there documentation that the patient was referred?
   - ○ Yes  ○ No
7. If your patient has a diagnosis of treatment resistant (intractable) epilepsy, were they referred to a comprehensive epilepsy center for additional management of epilepsy? Note: Epilepsy is treatment resistant if seizures continue despite adequate trials of two or more antiepileptic seizure drugs.

- Yes  
- No  
- N/A - Patient is not diagnosed with treatment resistant epilepsy.

**Health Care Transition**

8. For patients aged 13 years or older, is there documentation of an epilepsy transition plan of care?

- Yes  
- No  
- N/A - Patient younger than 13

- 8A. Has it been shared with the patient and/or caregiver?
  
- Yes  
- No

- 8B. Has it been updated in the past 12 months?
  
- Yes  
- No

**Optional: Counseling of Female Patients of Childbearing Potential**

9. For female patients of childbearing potential (12-24 years old): Was the patient counseled about how epilepsy and its treatment may affect contraception or pregnancy?

- Yes  
- No  
- N/A - Patient under 12 and/or male