

AMCHP

March 7, 2010

Washington DC



Ardis L. Olson, MD
Project Director

Elizabeth Pearson, PhD
Project Manager

Clinical Practice Guidelines

- Clinical guidelines are systematically developed statements to assist practitioners and patients in choosing appropriate healthcare for specific conditions.

The Institute of Medicine

Project Access

- Creating a system of care that enhances the capacity of primary care physicians and pediatric neurologists to co-manage the care of children and youth with seizure disorder:
 - Primary Care
 - Specialty Care
 - Community

Primary Care Goals

- Ensure PCP visits are proactive in helping patients/families manage their care
- Increase ability to manage children on AED's
- Establish consultation links between PCP and Neurology
- Change intervention from seizure only to comprehensive care
- Increase provision of educational material

Specialty Care Goals

- Provider education
- Enhanced communication between PCP, Neurology and Parents

Community Goals

- School nurse education
- Parent education and networking
- Connecting teens
- Regional workshops about coping with epilepsy

Definitions

- Referral: transfer of care
- Consultation: one-time or limited time
- Collaboration: on-going co-management
- Push registry: A report of those children in the general registry who have appointments scheduled within the next (30) days

Practice Setting

■ Primary Care

- Primary Care Clinics associated with larger hospital system
- Support for quality improvement activities
- Technology support
 - EMR's different at most sites

■ Specialty Care

- New Hampshire neurologists associated with DHMC system
- Maine Neurologists are independent privately owned practices

Community Resource Partners

- Title V
- Family Voices
- Partners in Health (NH only)

Existing epilepsy guidelines

- American Academy of Neurology
 - Guidelines currently being developed
 - Epilepsy
 - Efficacy and Tolerability of the New AEDs (Update)
 - Magnetoencephalography (Update)
 - Vagus Nerve Stimulation (Update)
 - Presurgical Neuroimaging in Epilepsy
 - Treatment of Adult with First Unprovoked Seizure
 - Generic AED Quality and Safety

Existing epilepsy guidelines

- National Institute for Health and Clinical Excellence (Great Britain)
 - Primarily adult focused
 - Pediatric recommendations with no specific decision tree
 - Team based approach for co-morbidities
 - Recognizes need for family centered approach
 - Youth participation in education and transition planning
 - Collaboration with PCP

Limits of current guidelines

- Purely medical (although acknowledges need for psychosocial and mental health assessment)
- Seizure diagnosis and treatment only
- No guidance on co-management strategies

Challenges to implementing practice co-management guidelines

- High psychiatric co-morbidity, limited resources
- Communication is sometimes inconsistent between PCP and Specialty care
- IT systems inconsistent even within affiliated health care organizations
- Quality improvement process is easily side-tracked
 - Staff changes (particularly administrative staff)
 - Silos within health systems (clinical improvement separate from non-clinical improvement structures)

Key to success

- Integrating into larger quality improvement for larger population of CSHCN
 - Consistent with medical home and chronic care model

Chronic Care Model



Key elements

- What do you think the key components would be for guidelines that would work in your practice?

Guideline development process

- What are the points of agreement?
 - What does neurology own
 - What is better managed at local PCP level?
- What works well?
 - PCP focus groups
 - Neuro interviews in both states
 - Family survey and parent partners
- Where are the gaps?

Key components

- Registry
- Referral path
- Co-management
 - Diagnosis and Treatment plan (specialist)
 - Ongoing management (PCP)
- Consistent patient education
- Established method of communication
- Planned PCP visit

Registry is first priority

- Name, Age, DOB
- Diagnosis
- Last Well Child Exam
- Next Well Child Exam
- Last Neuro Appt And Name Of Neurologist
- Next Neuro Appt
- Medications
- Care Plan
- Seizure Action Plan
- Pcp
- Tests (EEG,
- Complexity index score

Push registry

- Report of those patients with visits within the next month
 - Initiate care plan development
 - Screening for mental health
 - Complexity score

Planned visit

- Mental health screening
- Care plan development
- Education
- Community Resources

Planned visit note template

- See handout



Evidence Based Epilepsy Guidelines

Pediatric & Adolescent Medicine

Developed in collaboration with the Dartmouth-Hitchcock Department of Pediatrics, Section of Pediatric Neurology, Hood Center for Children and Families and Dartmouth Hitchcock Keene with support for resources from the Maternal Child Health Bureau.

References:

Epilepsia, 47(12):2011-2019, 2006, Blackwell Publishing< inc. 2006 International League Against Epilepsy. Original Research. Development of Performance Indicators for the Primary Care Management of Pediatric Epilepsy: Expert Consensus Recommendations Based on the Available Evidence

Hood Center for Children and Families, http://hoodcenter.dartmouth.edu/research-programs/chronic_illness/current.html

DHMC Regional Primary Care Center,

http://intranet.hitchcock.org/hc/webpage.cfm?site_id=1&org_id=352&morg_id=0&gsec_id=27146&item_id=33894

Goals and Measures

1. Establish a registry of all pediatric patients with Epilepsy	Active patients (patients who have been seen in the office in the past 2 years) with active problem diagnosis epilepsy (ICD-9 code 493%) on problem list.
2. Complexity/Severity Assessed	HOMES Complexity Scale Score documented in chart and registry
3. Medication List Updated and Given to Patient	% of patients with updated medication list at time of yearly planned visit
4. Screening for Medication Side Effects	% of patients with documented chart note of discussion of side effect screening
5. Learning, Behavioral and Mental Health Screening	% of patients screened using Pediatric Symptom Checklist and/or developmental screening
6. Seizure Action Plan Established	% of patients with completed Seizure Action Plan in chart
7. Timely Labs and Test available	% of patients with blood levels in the past year for medications that require blood level monitoring
8. Health Care Transition Plan for Adolescents age 16 or older	% of patients who receive education for transition planning documented in chart note.
9. Provision of appropriate educational materials	Documentation of type of materials distributed to patient

Epilepsy Co-Management

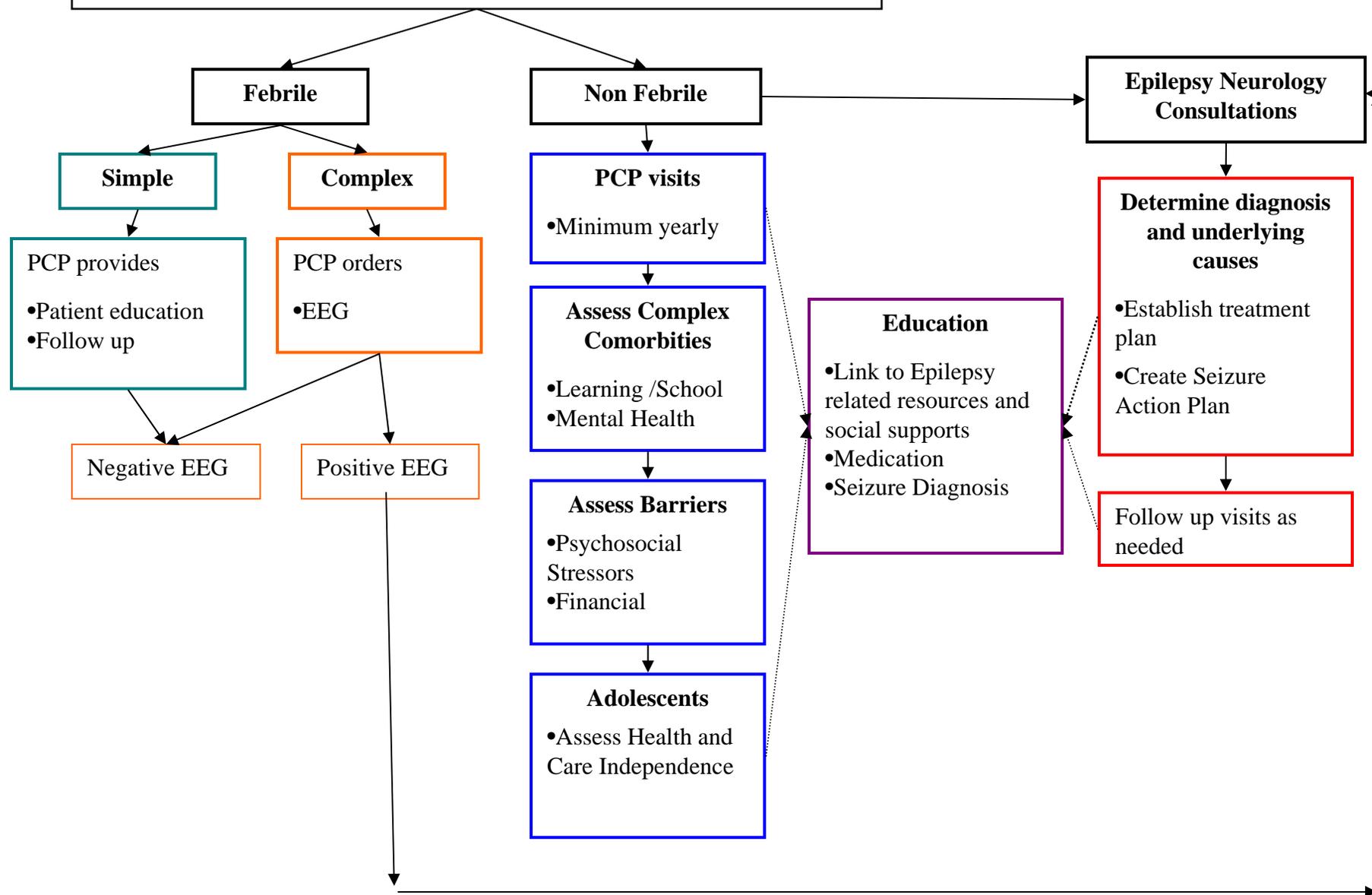
Primary Care

- Yearly planned visits
 - Pre-visit screening for co-morbidities and barriers to care
 - Assess school / learning issues
 - Care Coordination Plan for all high complexity children, desirable for lower level complexity children
 - Behavioral health screening
 - Seizure action plan for all children with neurology guidance
 - Educational materials
 - Updated medication list given to family

Specialty Care

- Establishes Diagnosis
- Documents Frequency and type of seizure
- History of medications used and side effects
- Ongoing medication management
- Seizure Action Plan for complex children
- Patient/Family Education
- Side effects discussed and documented in chart
- Labs and tests available at visit
- Updated medication list given to family

Epilepsy Initial Presentation



4 Components of Epilepsy Primary Care

•Assessment and Monitoring

•Address Co-Morbidities

•Education

•Medications

Assessment and monitoring

- Assess seizure type and severity to initiate therapy
- Communication with pediatric neurologists for medication co-management decisions
- Schedule follow up care every:
 - o 6 months for complex children with co-morbidities
 - o 12 months for children with well-controlled seizures
- Complex children with co-morbidities meet with Care Manager/Care Coordinator to create comprehensive care plan

Education

- Newly diagnosed patients
 - Parent Guide*
 - Your Child Today and Tomorrow*
 - Issue specific information
- Adolescents
 - oReady, Get Set, Go!*
 - Healthcare transition plan for all adolescents 16 and older
- Integrate education into all points of care

Emergency

Seizure action plan created by neurology and documented in medical record. Copy of seizure action plan given to parent to share with family, school nurse, day care or other care providers, social service agency case manager, camps, etc. as needed.

Medications

- Co-management decisions between PCP and Neurologist
- Side effects discussed and documented in chart
- All parent/child questions answered
- Education about medication its purpose, potential adverse reactions/side effects, and lab levels (as needed).

Key Activities

- Seizure Action Plans
- Screening for Learning/Behavioral issues
- Flow of work improvements
 - Medication lists
 - Post visit parent survey
 - Educational materials
- Training for primary care providers
 - Topics based on primary care needs assessment
- Practice guidelines

Challenges

- Primary care tends to be reactive
 - difficult to get traction for change
- Practice / Providers operate independently, even in same system
- Varying level of access to registry support within sites
- Technology (differing EMR, access to make changes, inconsistency of coding information)
- Need for broader community based education to maximize use of care plans

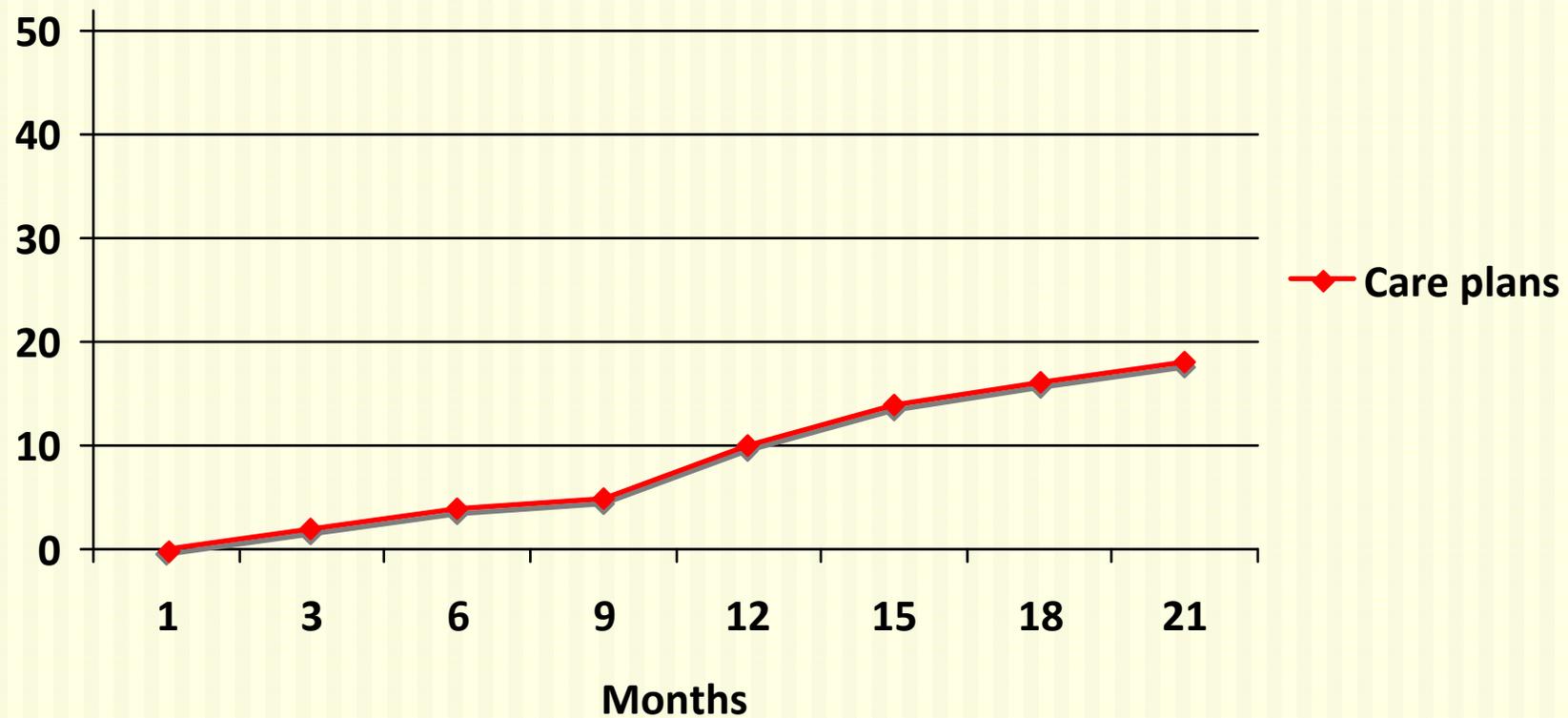
Challenges

- Neurologists tend to function independently with few resources to implement change in their clinic system
 - Narrowly defined role
 - Recognize co-morbidity impact, reluctant to own it
 - Informal vs. formal screening
 - No formal process for referral and management
 - Families need local mental health support
 - Few mental health providers trained in needs of CSHCN, especially diagnosis specific needs
 - Lack of time to address learning/behavioral issues

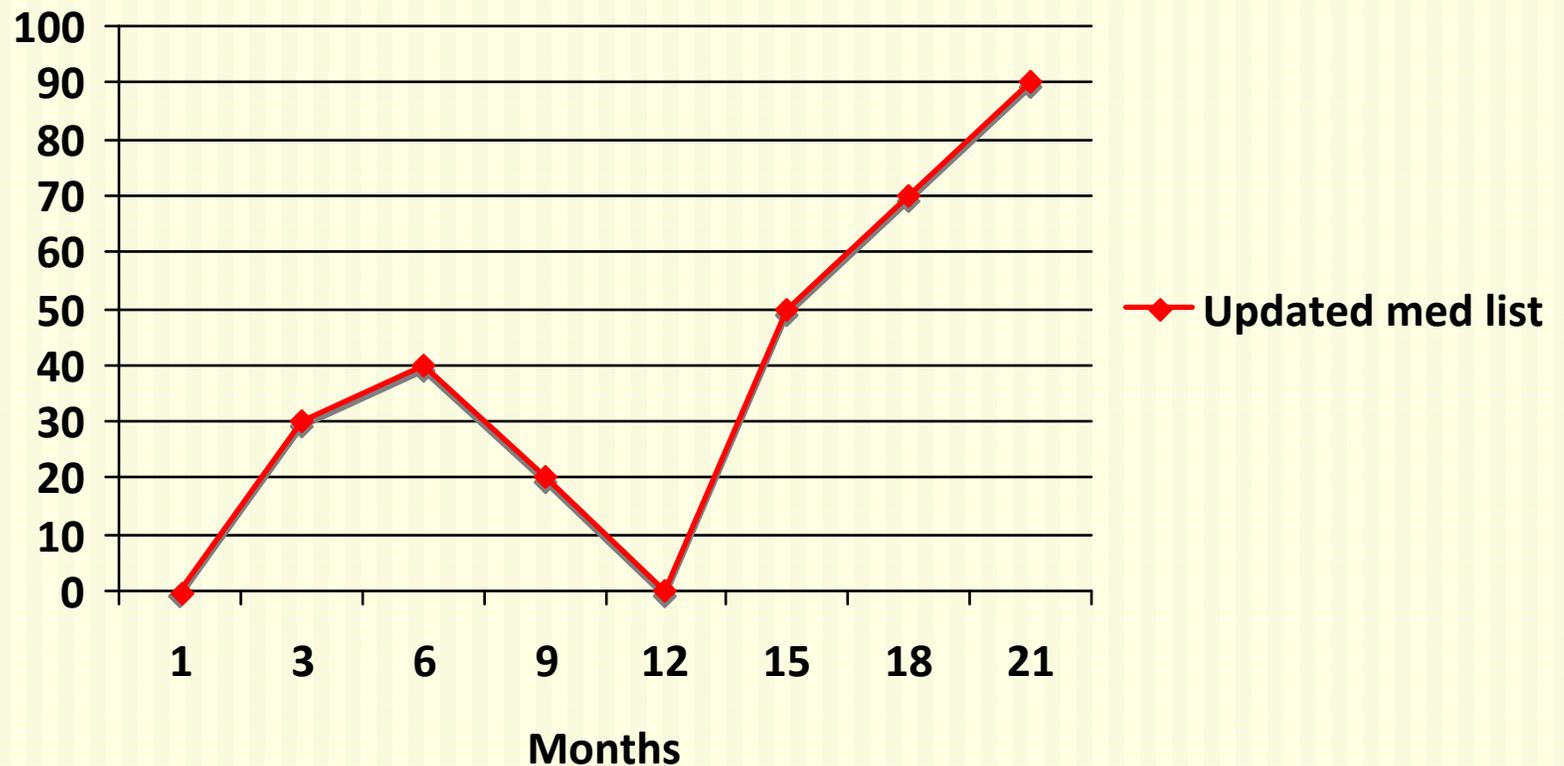
Lessons Learned

- Epilepsy population as a model for change will benefit the larger population of CYSHCN in the practice
- Work goes slowly
 - Need resources to maintain work for 12 - 18 months before measurable change in system

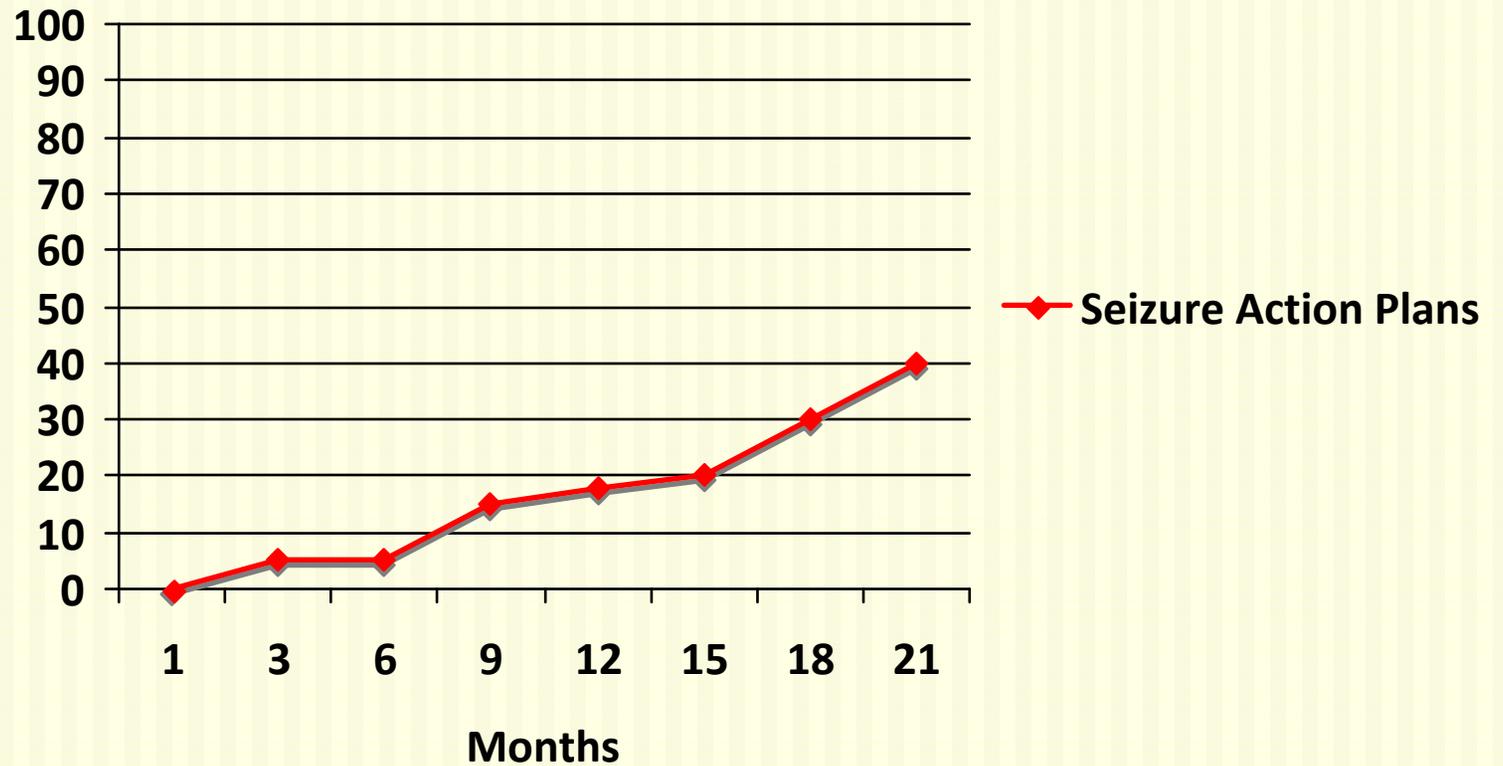
Planned Visit Progress



Medication List Updated and Given to Patient



Seizure Action Plans



Lessons Learned

- External change agent necessary
 - May be parent partner
 - Mentor for active team participation
 - Distinct role/task early in process
 - Comfortable functioning in medical culture
 - Knowledge of field
 - Knowledge of application of QI model
 - Highly organized and ability to facilitate meetings

Conclusions

- Practice guidelines do lead to change in the system but take extensive clinical and non-clinical staff commitment and time to develop and implement
- Parent partners are vital to sustaining momentum for practice change
- External change agent needed to organize and facilitate process, encourage and reflect progress to team