

Enhancing the System of Services for Children and Youth with Epilepsy



HRSA, MCHB, Division of Services for Children
and Youth with Special Healthcare Needs



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Phase 3

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Phase 1

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Pictured on cover: The Koehlmoos Family of Nebraska: Andrew, Jason, Christopher, Jennifer and Matthew

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Overview of Maternal and Child Health Bureau Core Outcomes and Background

In order to establish and support the foundation and structure of a system of services for children and youth with special health care needs that is family-centered, coordinated, and community-based, the Health Resources and Services Administration Maternal and Child Health Bureau (MCHB) has identified the following six core outcomes that provide a framework for resource allocation. The MCHB funds national centers to advance the achievement of each through information exchange and technical assistance:

- ✦ **Families of children and youth with special health care needs partner in decision making at all levels and are satisfied with the services they receive;**
- ✦ **Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home;**
- ✦ **Families of CSHCN have adequate private and/or public insurance to pay for the services they need;**
- ✦ **Children are screened early and continuously for special health care needs;**
- ✦ **Community-based services for children and youth with special health care needs are organized so families can use them easily;**
- ✦ **Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.**

✦ **Project Access**, a national initiative of the **Maternal and Child Health Bureau of the Health Resources and Services Administration**, was a three-phase project funded to increase awareness and provide education, improve the quality of services for children and youth with epilepsy, and promote a medical home model that provides coordinated, comprehensive care services for children and youth with epilepsy. It was grounded in a collaborative approach that involved state agencies, physicians, other health care providers, families, schools, and community resources to improve access to comprehensive, coordinated health care and related services for children and youth with epilepsy residing in rural and medically underserved areas. A major tenet in development of patient- and family-centered systems of care is engagement of consumers in the process of developing and improving services.

Purpose

This toolkit provides practical advice and guidance to families, educators and caregivers working to engage families in the process of improving systems of care for children and youth with epilepsy and other special health care needs, to improve community-based access to specialized medical services, and to improve the quality of care coordination in school settings.

How to Use This Toolkit

The toolkit is organized into six sections—*Overview of MCHB Core Outcomes and Background*, *Engaging Families: Fostering Parents As Partners In Improving Systems Of Care For Children And Youth With Epilepsy*, *Increasing Capacity For Care Coordination Across Settings*, and *Organizing Community-Based Services for Family Accessibility*. Each of the sections on engaging families, coordinating care, and organizing community-based services begin with information about why this issue is important, and then includes specific examples describing innovative approaches to addressing them. Each section also includes relevant resources and tools that have been useful and may be helpful to others. Website addresses are provided where available and links are marked by the cursor symbol (↗). Tools that are not available on the website are included in the appendices.

The Data Resource Center for Child and Adolescent Health estimates that there are 345,339 children in the United States with a diagnosis of epilepsy or seizure disorder.¹ The Institute of Medicine (IOM) Report “Epilepsy Across the Spectrum: Promoting Health and Understanding” released in 2012, noted a need to increase awareness of the complex medical and social needs of people with epilepsy, and recommended engaging people with epilepsy and their families in educating, disseminating, and advocating for improved care and services.² The IOM also recognized a need for educating health care providers in order to prepare the healthcare workforce to provide effective family-centered diagnostic, treatment and management services that take into account health literacy as well as cultural and psychosocial needs, and fosters self-management.³

Resources

- ↗ **Institute of Medicine Report:**
Epilepsy across the spectrum: Promoting health and understanding. Washington, DC: The National Academies Press. 2012.
- ↗ **National Center for Project Access**
- ↗ **Maternal and Child Health Bureau of the Health Resources and Services Administration**
- ↗ **Epilepsy Foundation**

1 Data Resource Center for Child & Adolescent Health. (2012). The Child and Adolescent Health Measurement Initiative. Retrieved September 20, 2013, from <http://www.childhealthdata.org/>

2 Institute of Medicine. (2012). Epilepsy across the spectrum: Promoting health and understanding. Retrieved September 20, 2013, from <http://www.iom.edu/Reports/2012/Epilepsy-Across-the-Spectrum.aspx>

3 Institute of Medicine. (2012). Epilepsy across the spectrum: Promoting health and understanding. Retrieved September 20, 2013, from <http://www.iom.edu/Reports/2012/Epilepsy-Across-the-Spectrum.aspx>

Engaging Families:

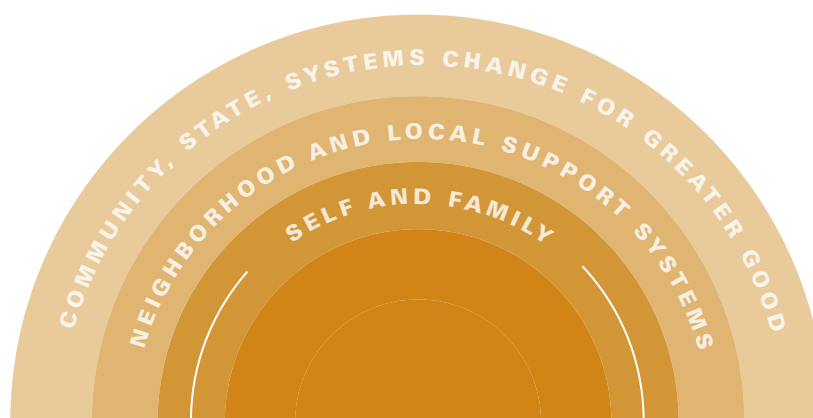
Fostering Parents as Partners in Improving Systems of Care for Children and Youth with Epilepsy

Collaboration among families and professionals is required in order to provide quality care for children and youth with epilepsy and other special health care needs. Family members provide individual consumer perspectives that offer a sense of reality to the work of providers. Engaging parents and other family members in the process of improving systems of care ensures that programs and policies actually meet the needs of individuals and families. Parents act as caregivers, advocates and decision-makers — all skills that are needed at every system level.⁴ Engaging parents and families has benefits to the individual family, their communities, and the system of care, and formalizing a parent role in systems improvement is a strategy for realizing these benefits.

The Concentric Model of Parent Leadership can help to understand the various roles of families at different system levels. Ultimately, parent leaders develop through their personal experiences, gaining in their ability to expand a focus on family to consider their role in improving systems for the greater good of all children. Parents' experience with the system of care for children with special health care needs starts at the center of the model. Some parents remain in that "inner ring", managing the care of their children and family. This level of parent leadership involves developing knowledge and applying skills to effectively engage in family-provider relationships. Some parents' involvement stays at this personal level. However, many parents move out of the inner ring to become more involved in their communities, promoting family-provider relationships with others, and some become catalysts for change, working as advocates to improve systems of care for all children. Even as parents develop as leaders and move to the "outer ring", family needs will draw them back to the center as needed. However, when support for family or parent engagement is in place, parents are able to move from the inner circle to the outer circle more quickly and effectively.

➤ **The Parent Leadership Training Institute** defines parent leadership as "...the capacity for parents to interact within society with purpose and positive outcomes for children."

Figure 1: The Concentric Model of Parent Leadership⁵



⁴ <http://www.pacer.org/health/>

⁵ Aquino, E., Bristol, T. E., Crowe, V., DesGeorges, J., & Heinrich, P. (n.d.). *Powerful partnerships: A handbook for families and providers working together to improve care*. Retrieved September 20, 2013, from http://www.nichq.org/resources/powerful_partnerships.html

One way to support parent engagement is through leadership training, such as trainings provided by the University of Vermont, Parent Advocacy Coalition for Educational Rights (PACER) Center, the Parent Leadership Training Institute, and the Parent to Parent Organization (P2P USA).

Parents as Collaborative Leaders: Improving Outcomes for Children with Disabilities is a national partnership between the University of Vermont, the PACER Center, and several other parent and advocacy organizations. The project developed research-based training support for parents of children with disabilities in becoming active leaders in policy development and evaluation. Through this project, the team developed a collaborative leadership core curriculum with ten modules and implemented leadership internships for parent leaders. The collaborative leadership modules can be accessed as PowerPoint slides on the program website (see TOOL 4 for the website).

Family Leadership Training Institute (FLTI) is a public-private partnership that works with communities to provide parents, caregivers and other interested adults with the knowledge, skills and tools for effective civic engagement. Using a facilitated process, FLTI programs include a day-long retreat and 20 weekly sessions focusing on developing personal leadership skills and practicing civic and democracy skills (see TOOL 2). FLTI aims to increase parent-child interactions and improve child outcomes through parent/caregiver involvement, expand the capacity of participants as change agents for

Tool 1: Parents as Collaborative Leaders Curriculum

Module 1: Defining Parent Leadership
Module 2: MAPS for Leadership
Module 3: Critical Elements of Collaboration
Module 4: Stages of Group Development
Module 5: Tips for Leading Effective Meetings
Module 6: Listening & Asking Clarifying Questions
Module 7: Understanding Conflict - Version 2

Tool 2: Family Leadership Training Institute Course Content

The 20-week Family Leadership Training Institute course includes instruction on:

- Understanding personal history and its impact on perceptions of leadership
- Thriving and working with diversity
- Assessing and defining problems - thinking critically
- Using the media
- Public speaking
- Using benchmarks and outcome measures
- Forming useful coalitions and building community
- Working with and learning how to engage the opposition
- Understanding policy and municipal budgets
- Becoming familiar with city, state and federal laws

children and families, and facilitate systems change for family involvement through their engagement in policy and process decisions.

➤ **The Parent to Parent Organization (P2P USA)** is a national non-profit organization committed to promoting access, quality and leadership in parent to parent support across the country. P2P USA parent support is defined as the intentional connection between a trained volunteer *Support Parent* and a parent seeking information, resources, guidance, and support from an experienced parent. This evidence-based program facilitates parent “matches” and provides follow-up support to assure the matched relationship meets expectations. P2P USA provides detailed instructions for implementing a parent support program, based on ongoing evaluation, with several guidance documents found at the P2P USA website (See TOOL 4 and also TOOL 7: Additional Resources for Parent Recruitment, Training and Support Box). Matches may be in place for a few visits, or may become lifelong friendships. The leadership development skills that programs such as these support prepare parents for active roles in improving systems of care.

Tool 3: P2P USA Endorsed Matching Practices

- “Match” a parent seeking support with an experience parent within 24 – 48 hours of referral
- Identify a “match” parent based on information about the referred child’s disability, parent’s situation, needs, special challenges, qualities looking for in a support parent, and preferences regarding a “match”
- Support parents should make at least four contacts within the first eight weeks: first within 24-48 hours of referral, at two weeks, four weeks and eight weeks.
- Follow-up calls to both parents within 2-3 days and at eight weeks to ensure that the “match” is appropriate.
- Provide formal Support Parent training prior to being matched to allow them to hear others’ experiences and stories.

- P2P USA

Project Access aimed to integrate families of children and youth with epilepsy, and children and youth with epilepsy themselves into the improvement process, over a three-phase process. Phases 1 and 2 focused on raising awareness and access to care for children and youth with epilepsy. Phase 1 (2004-2007) broke new ground in developing family-centered services by including parents of children and youth with epilepsy in the improvement process. Parents were also included in Phase 2. One of the outcomes of Phase 2 (2007-2010) was the publication by the National Initiative of Children’s Healthcare Quality of ➤ **Powerful Partnerships: A Handbook for Families and Providers Working to Improve Care**, which highlights the invaluable contributions of families to quality improvement teams and provides guidance for including families in the process of improvement.

Examples of parents’ engagement in Leadership Development, Care Coordination and Rural Outreach are described below, including materials that supported the success of the projects.

Project Access Phase 3 was designed to engage families in the process by implementing some of the valuable lessons of Phases 1 and 2. Project Access grantee teams were required to include youth AND family members on their quality improvement teams, and their contributions to shared learning were enthusiastically recognized by Project Access teams. However, it happened through the intentional efforts of a parent leader who had a faculty role in the learning collaborative, serving as family liaison between other faculty and team quality improvement team members. See TOOL 3.

Parent Role in Leadership Development

An important role of an outer ring Parent Leader is fostering the development of other parent leaders. When parents are recruited to quality improvement teams, they may or may not have specific quality improvement knowledge or be comfortable working with a team of providers. See TOOL 3 for tips for providers working with parents in learning collaboratives and TOOL 5 for tips for supporting families members engaged in a learning collaborative.

Tool 4: Tips for Supporting Parents and Family Members Engaged in a Learning Collaborative

Role of the Parent Leader in Leadership Development: Tips from an Expert

1. **Assess faculty experience working with parents in leadership roles.** Faculty with limited experience will require extra attention to prepare them for their unique role in building parent leaders, which includes mentoring other team members.
2. **Assess team members' understanding of the parent leadership role.** This information is essential early in the process as teams must recruit parent partners to their teams. It is important that this is understood prior to the first learning session, so that parents are recruited and scheduled to attend learning sessions. Lack of understanding, lack of budget or lack of support from the faculty in communicating the importance of family role, can cause the process to stall.
3. **Support team members in recruiting family team members.** Teams without experience partnering with parents often have many questions, such as:
 - a. How do I find these parents?
 - b. What characteristics should I look for?
 - c. What will they be doing?
 - d. What am I asking them to do?
 - e. How do you ask busy parents for time?

4. **Take care of the parents.**

- a. **Support parents' active participation as team members.** Parent experience of the first learning session can set expectation and tone for the work to follow.
 - b. **Sponsor a dinner for family members on-site on the evening prior** to the morning start of the learning session. This dinner serves many purposes. It provides an opportunity for parents to meet and bond with each other, and share their stories. It provides an opportunity to assess where they are in their journeys and what coaching they might need. Finding time to meet with them alone following this formal dinner is tricky as they need to spend time with their teams to establish relationships and allies.
 - c. **Provide moral support and mentoring.** This dinner also validates the importance of their participation, and provides a time for questions and answers about what to expect of the learning session over the next few days, and an opportunity for the Parent Liaison to encourage them to speak up with their team, and provide some history about how family engagement has impacted previous learning collaboratives. It is not unusual to find families at the first learning session who have no understanding of what the project is all about!
 - d. **Support and coordinate logistics:** Travel, hotel problems, phone issues, last minute emergencies, money concerns, forgot something.
 - e. **Provide resources:** You can't expect families to do a good job for others if they have needs, questions or problems.
5. **Ongoing support:** During team time at learning session, monitor the parents and ensure they don't have questions, are engaged and speaking up. Work with other faculty and team leaders if there are problems and coach the families on ways to get involved. Monthly conference calls provide facilitated meeting times for regular and consistent check-ins to support continuous engagement of family team members.

"I have learned over the years the best most fruitful conversations come out of casual conversations. Sharing experiences and backgrounds allows professionals to understand better the tools and skills that parents bring to the project. So time with the team at meals and off hours is critical to success."

- Christy Blakely, Parent Liaison and Project Access Learning Collaborative Faculty Member

Tool 5: Tips for Providers Working with Parents in Learning Collaboratives

1. Identify early a parent leader with expertise in the specific focus area for a Learning Collaborative or other quality improvement activity. Look for parent leaders with qualities such as:
 - Parent of a child or young adult
 - Able to go beyond the center ring of the Concentric Circle Model of Parent Leadership
 - Is passionate about the need for change Understands and can communicate the purpose of the Learning Collaborative
 - Able to travel
 - Able to facilitate meetings
 - Skilled at empowering parents
 - Good writer
 - Attached to other parent resources in the state and possibly across the country
 - Committed to attending faculty and parent calls with appropriate schedule accommodations
 - Insightful with interpersonal dynamics
 - Good public speaker
 - Self-starter
 - Approachable
 - Culturally sensitive and respectful of differences
 - Good listener
 - Good sense of humor
 - Big picture thinker
2. Include parent/family partners in all planning meetings from beginning of collaborative and strategize ways for parents to be involved in the system changes of the team.
3. Tangible outcomes assist families in getting involved – for example, developing seizure action plans and care notebooks or care plans in the epilepsy Collaborative were initiatives begun and carried out by parent partners.
4. Support a parent partner as a leader by giving him/her a role in the agenda – for example, a presentation at one of the collaboratives or leadership on a test of change.
5. Follow-up with parents who don't attend team calls or meetings.

- "Powerful Partnerships" NICHQ

Parent Role in Care Coordination

Grace's Hope Hospital Visitation Program

Alysia Peddy, a parent partner on the Florida Project Access Team, remembers the years she spent with the diagnosis of epilepsy for her son, Pierce, with no one to talk to about parenting a child with a long-term chronic condition. The feeling of being “all alone” was all too real and guided the development, with the support of Thomas Orth, Executive Director of the Epilepsy Services Foundation, Inc., of the Grace's Hope Hospital Visitation Program at St. Joseph Children's Hospital. The program was developed to provide support to families of children newly diagnosed with epilepsy, or families of children with epilepsy who have experienced little or no support. Named for her daughter, the project moved from one Mom's wish to the reality that a doctor with a newly diagnosed child can choose Grace's Hope on the hospital referral form. The referral will connect the family with a trained volunteer who will visit the family and provide resources, information, a friendly face and support.

The 7.5-hour training, developed in collaboration with St. Joseph Children's Hospital, consists of completing the HOPE Train the Mentor Program, a Listening Skills Program, and the Hospital Volunteer Services Training Program. Grace's Hope volunteers are people with epilepsy or parents of children with epilepsy. A representative from the hospital also attends the HOPE Train the Mentor Program as an orientation and serves as a liaison between the program and the hospital, sharing program information with staff in the pediatric neurology department, nurses, technicians and administrators. Volunteers are provided with a Grace's Hope “Goody Bag” which includes informational materials for families, and guidance about their volunteer roles, such as when to visit and questions to ask of families. The program provides formal group support for the volunteers. The challenges for Ms. Peddy and the others involved in Grace's Hope are making doctors aware of this project and encouraging referrals.



Topics Covered in the Grace's Hope Listening/Hearing Training

Introduce yourself as a volunteer of Epilepsy Services Foundation, Inc. (ESF)

If you were in the hospital, what would you want from the volunteer?

Importance of listening and hearing their story

- Listen to words
- Listen to body language: anxiety, anger, distress, tiredness

What to do if they ask a question?

- Answer it if you are sure you know it. But remember, misinformation is as bad as wrong information.
- Refer them to Q&A 101
- Let them know you don't know and tell them you will follow up and get an answer.
- Let them know they asked a good question and should ask their doctor.

With the support of the Epilepsy Foundation of Florida and Project Access, this program is being reviewed for implementation by other hospitals in Florida, as well as other states. Each hospital will have its own volunteer requirements, but the HOPE Train the Mentor Program will be part of any training for Grace's Hope volunteers at any hospital. Grace's Hope Hospital Visitation Program has been funded with support from the **Epilepsy Services Foundation, Inc.**, and proceeds from the sale of the small purple felt hearts Ms. Peddy's daughter and friends sew and distribute.

Parent Role in Rural Outreach

L.E.A.P. to Understanding –

The Local Epilepsy Awareness Project

The Epilepsy Foundation of Western/Central Pennsylvania, in collaboration with the Epilepsy Foundation of Eastern Pennsylvania, partnered with the Bureau of Family Health Special Kids Network in a rural outreach/ community engagement effort. The main goal of the effort was to better understand the needs and service gaps of children and youth

with epilepsy and their families in order to inform strategic planning. This team recruited Parent Facilitators to serve in a leadership role for this initiative, and developed materials to support the role. The Parent Facilitator leadership role included:

1. assisting in identifying other community stakeholders who could participate in the epilepsy information gathering meetings,
2. gathering and providing information on issues pertaining to children/youth with epilepsy and other special health care needs,
3. providing feedback and suggestions to inform a regional and statewide strategy, and
4. following up on meetings and project activities.

Having formal guidelines in place supported the process by outlining clear expectations, requirements, and processes. Examples of the tools that guided their process are included in the appendices (TOOL 6).

The Grace's Hope Goody Bag includes these items:

- A one-page summary of Graces' Hope Hospital Visitation Program
- An information sheet about Project Access
- A handout of medicines for epilepsy
- A copy of Epilepsy Advocate
- **Epilepsy Advocate Glossary of Terms** ➤
- A Contact Form
- First Aid flyers
- **101 Epilepsy Questions & Answers** ➤
- **Seizure Control Calendar** ➤
- Epilepsy Services Foundation's brochure
- A Resource and Community Service Manual for Hillsborough & Pinellas counties
- A coloring book & crayons or toy for the children
- A Graces' Hope heart pin

Tool 6: Local Epilepsy Awareness Project (LEAP) Materials

Resources

- Appendix A: LEAP Project Description
- Appendix B: LEAP- Rural Outreach Facilitator Guidelines
- Appendix C: LEAP to Understanding Training Agenda and Process Plan
- Appendix D: Meeting Evaluation Sample

Tool 7: Additional Resources for Parent Recruitment, Training and Support

➤ **Family to Family Health Information Centers (F2F HICs)** are non-profit, family-staffed organizations funded by HRSA Maternal and Child Health Bureau that help families of children and youth with special health care needs and the professionals who serve them by providing information, advice and resources. F2F HIC staff are parents and family members of children with special health care needs who have first-hand experience navigating national, state, and local systems of care.

➤ **Parent to Parent USA (P2P USA):** is a national non-profit organization committed to promoting access, quality and leadership in P2P support across the country. This site highlights statewide organizations that have P2P support as a core program and demonstrate a commitment to implementing evidence-based P2P USA endorsed practices.

- **P2P USA Guidance for Recruiting and Training Support Parents** ➤
- **P2P USA Endorsed Practices for Matching and Follow-up** ➤
- **P2P USA Endorsed Practices for Parent to Parent Support** ➤

➤ **Family Voices:** Family Voices is a national non-profit organization that aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Family Voices provides families with tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care. (continued on following page)

➤ **One-pager** produced by the National Center for Families and Professional Partnerships describes the past and current work of Family Voices as a strong partner in the Maternal and Child Health Arena, including discussion of the Value of the Family Voice in Improving Health Outcomes & Costs.

➤ **Powerful Partnerships: A Handbook for Families and Providers Working to Improve Care:** Produced by the National Initiative for Children's Healthcare Quality, this handbook highlights the invaluable contributions of families to quality improvement teams through lessons learned in Phase 2 of Project Access, and provides guidance for including families in the process of improvement.

➤ **Parent Leadership Training Institute (PLTI)SM** enables parents to become leading advocates for children. The PLTI teaches parents how to become practiced change agents for the next generation. Parents participate in the curriculum development, evaluation, and outcomes. Each class of parents mentors the next class, to foster community caring and developing a coalition of parent leaders. Family supports, such as child care, are included.

➤ **Parents as Collaborative Leaders:** A collaborative research project hosted by the University of Vermont and ➤ **PACER Center**, with funding provided by the US Department of Special Education Programs, and the National Institute of Leadership, Disability, and Students Placed at Risk.

Increasing Capacity for Care Coordination across Settings

Epilepsy touches children and youth where they live, learn and play. The complex needs of children and youth with epilepsy underscore the importance of care coordination as a key strategy for improving health care system effectiveness, safety, and efficiency.^{6, 7, 8, 9} Ensuring that the right services are provided at the right time requires coordination between providers and families, and all others who come into contact with children and youth with epilepsy.

Increasing Capacity to Provide Services in School Settings

Ensuring that services are available in school settings and other locations where children spend a significant part of their day requires effective communication between providers in various settings. The use of Seizure Action Plans (TOOL 8) ensures that personalized medical information about a student's epilepsy - including emergency contacts, medications, seizure triggers, and actions to take in specific situations - is available where children are most likely to need it. A Seizure Action Plan is generated by a student's health care provider, and should be updated at each visit to reflect any changes in treatment. The increasing use of electronic medical records (EMR) supports standardization of Seizure Action Plans, ensuring that relevant information is included. Seizure Action Plans can be embedded in a child's EMR, so it can be automatically generated at each patient-provider interaction.

Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves aligning personnel and other resources needed to carry out all required services, and is often managed by the exchange of information among participants responsible for different aspects of care.

- Agency for Healthcare Research and Quality

- 6 McDonald KM, Sundaram V, Bravata DM, et al. Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies (Vol. 7: Care Coordination). Rockville (MD): Agency for Healthcare Research and Quality (US); 2007 Jun. (Technical Reviews, No. 9.7.) 3, Definitions of Care Coordination and Related Terms. Available from: <http://www.ncbi.nlm.nih.gov/books/NBK44012/>
- 7 Adams, K., & Corrigan, J. M. (2003). Priority Areas for National Action: Transforming Health Care Quality. Retrieved September 20, 2013, from <http://www.nap.edu/openbook.php?isbn=0309085438>
- 8 Antonelli, R. C., McAllister, J. W., & Popp, J. W. (May 2009). *Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework*. New York, NY: The Commonwealth Fund. Available from: <http://www.commonwealthfund.org/Publications/Fund-Reports/2009/Apr/Improving-Care-Coordination-Case-Management-and-Linkages.aspx>
- 9 Antonelli, R. C. (October 26, 2009). Presentation: Family-Centered Care Coordination: The Driver for Advancing Pediatric Health Care Quality *Title V MCH Federal/ State Partnership Meeting*. Available from: http://webcast.hrsa.gov/conferences/mchb/partnershipOctober2009/slides/monday/2.4.2_Antonelli.pdf

Tool 8: What is a Seizure Action Plan?

What is a Seizure Action Plan?

A Seizure Action Plan (SAP) is a document that provides detailed health and medical information about a student and his/her epilepsy or seizure disorder*. Usually, the SAP provides guidelines as to how to respond when a student is experiencing a seizure. This document will include input from the student's guardian, physician and/or neurology specialist.

Who uses it?

Every individual who interacts with a student who has a seizure disorder will benefit from this information. Specifically, school teachers, school nurses, coaches, and other individuals with supervisory roles, should receive and review the SAP.

Where is it kept?

Typically, school nurses serve as the "gatekeeper" of the SAP. It is advisable for a school nurse to have the SAP in the student's file; and, the classroom teacher(s) should have a copy. Parents and physicians usually keep a copy as well.

Why is it necessary?

If a student has been diagnosed with epilepsy the child and his/her family will likely not consider a seizure an emergency. Unfortunately, most of the time seizures are treated as an emergency. Often, 911 is dialed. This creates unnecessary medical expenses and is embarrassing for the student. The SAP provides student specific information that will enable the most appropriate response for the student. It also provides information to explain when a seizure is an emergency and 911 should be dialed.

Who will benefit?

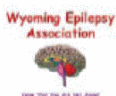
Everyone benefits from a SAP. Students are more likely to receive an appropriate response, school teachers and school nurses have the necessary information to respond and provide first aid, and parents are more at ease knowing that a written plan is in place.

Is there a cost involved?

No, a SAP is free provided that the student has access to, and visits, a physician treating their seizure disorder. The only cost involved is related to the time it takes to write and read the document.

How often is the SAP updated?

It will depend on the needs of each student and changes in his/her medical condition. Most students will have the SAP for the entire school year and maybe as long as they attend a given school. Students with more complex conditions may have their plan updated more frequently by their physician or medical specialist.



*The terms "epilepsy" and "seizure disorder" are synonymous and can be used interchangeably

Project Access: Improving Care for Children with Epilepsy is a grant (#H98MCO8579) from the federal Maternal and Child Health Bureau, Health Resources and Services Administration, awarded to the USC University Center for Excellence in Developmental Disabilities, Children's Hospital Los Angeles. The grant subcontracts with UCEDDs in Alaska and Wyoming, Family TIES of Nevada, and the Epilepsy Foundation of Northern California. The Epilepsy Foundation Northwest and the Epilepsy Foundation of Colorado also provide support. Two other partners in Project Access also provide support: the National Initiative for Children's Healthcare Quality (NICHQ) and the Epilepsy Foundation.

The University of Rochester Medical Center provided this sample of a Seizure Action Plan (TOOL 9) generated from an electronic medical record:

Tool 9: Seizure Action Plan embedded in the Electronic Medical Record

Hyperspace - SMH PEDS NEUROLOGY-AC6 - URMCD PRD - JENNIFER K.

Epic Home Schedule In Basket Pt Station Chart Encounter Telephone Call Archive eRecord Update Refill Medication Patient Lists

Workbench

SmartPhrase Editor

Name: KWSZACTPLAN ID: 127737

Content Owners & Users Synonyms

Rich text (bold, italics, etc.)

Arial 12 B I U A

School Seizure Action Plan

For @NAME@; Date Reviewed: @TD@

@NAME@ is being treated for a seizure disorder ("epilepsy"). The information below should assist you if @name@ has a seizure during school hours.

Who to Call:

Caregiver/Contact name	Phone number #1	Phone number #2

SEIZURE INFORMATION

Seizure Type	What Happens?	Usually Lasts for:	How Often?

Triggers?:

SmartLists

- Default
- Or
- None
- Sentence

<< Add



Short Description (250 characters max)
[Populate from SmartPhrase List](#)
 Seizure Action Plan

School nurses have an important role in providing services to children and youth with epilepsy. Nurses are essential to ensuring that care is coordinated, and that emergency seizure medications are properly administered. However, school nurses may not always be available when needed. In fact, wide variation exists in the number of school nurses per student in the United States, and not every school has a nurse on site.¹⁰ In states with very high ratios of students to school nurses, or where no nurse is available, the ability to administer emergency seizure medications could be limited. When a school nurse is not immediately available, other school personnel must respond to the immediate needs of children with epilepsy. Project Access teams conducted extensive educational outreach to school nurses, teachers, students, bus drivers, coaches, and others who may interact with children or youth with epilepsy, and developed several resources to support this process. TOOL 10 provides an overview of topics that should be included in training school personnel. TOOL 11 provides training materials for school bus drivers working with children and youth with epilepsy. Appendix J is a one-page assessment and action reference sheet for school nurses.

10 National Association of School Nurses. (2010). Healthy Children Learn Better: School Nurses Make a Difference. Retrieved August 16, 2013, from http://www.nasn.org/portals/0/about/press_room_faq.pdf

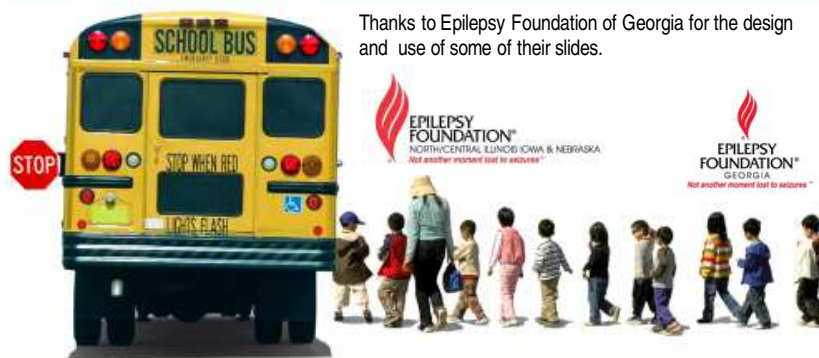
Tool 10: Epilepsy Training Topics for Schools

- What is a seizure?
- What is epilepsy?
- What do seizures look like?
- Appropriate first aid for seizures
- When is a seizure an emergency?
- Who has epilepsy?
- Dispel misperceptions about epilepsy
- Common seizure triggers (insulin, lack of sleep, fever, hormones, etc.)
- Prevent stigma and promote inclusion
- What is a Seizure Action Plan? How is it used?
- What is a Seizure Observation Form? How is it used?
- Seizures outside the classroom (field trips, playground, school bus, etc.)
- Seizures in a wheelchair
- Seizures in water
- Treatment for seizures

Robyn Neft, RN, CRNP, a Certified Pediatric Nurse Practitioner at the University of Pittsburgh Child Neurology Clinic, produced a comprehensive 40-minute, web-based video presentation. The presentation includes an overview of epilepsy, as well as treatment, emergency response, and academic and social implications. It is accessible through the Learning Center on the Epilepsy Foundation of Central/Western Pennsylvania: **Overview of Epilepsy-Managing Seizures in the School Setting.**  This presentation is available on YouTube video (The website is noted in TOOL 12). A set of presentation slides developed by the Epilepsy Foundation North Central Illinois, Iowa and Nebraska entitled *Seizure Disorders in Children: What School Nurses Need to Know* is attached in Appendix L. Additional resources developed by Project Access teams include an information sheet produced by the Epilepsy Foundation of Florida with guidelines for First Aid for Seizures (**available in English and Spanish** ). TOOL 13 provides guidelines for first aid to children in wheelchairs.

Tool 11: Epilepsy Training for School Bus Drivers

Epilepsy & the School Bus Driver



Thanks to Epilepsy Foundation of Georgia for the design and use of some of their slides.

Presentation funded by Health Resources and Services Administration's Maternal and Child Health Bureau, "Project Access – Nebraska-Telehealth for Children with Epilepsy" Grant # H98MC20270

Tool 12: More Resources for Increasing Capacity for Care Coordination across Settings

➤ **Overview of Epilepsy-Managing Seizures in the School Setting**, Robyn Neft, RN, CRNP, a Certified Pediatric Nurse Practitioner at the University of Pittsburgh Child Neurology Clinic

➤ **Guidelines for First Aid for Seizures**- In English and Spanish, Produced by the Epilepsy Foundation of Florida

The Epilepsy Foundation/Epilepsy Therapy Project has many resources:

➤ **Your Child at School and Child Care** – provides materials to support parents in educating school and child care personnel about caring for their child with seizures

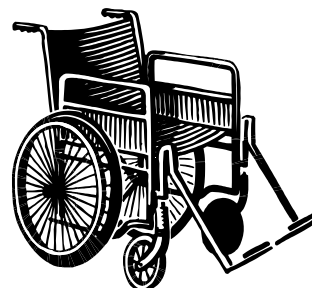
➤ **Managing Students with Seizures** – Includes questionnaires for parents of students with seizures, seizure observation record, seizure action plan in English and Spanish

Tool 13: First Aid for Seizures in a Wheel Chair

Leading the fight to stop seizures, find a cure and overcome the challenges created by epilepsy.

Do :

- ✓ Stay with the person
- ✓ Time the seizure
- ✓ Apply the wheelchair brakes
- ✓ Leave person in chair with seatbelt on
- ✓ Recline backrest only—do NOT tilt chair
- ✓ Lean person slightly to one side to aid drainage of any fluid/food in mouth
- ✓ Support head and protect airway
- ✓ After seizure has stopped, carefully remove from chair and place in recovery position—lying on side, if possible.
- ✓ Observe and reassure until completely recovered.



Do Not:

- ✗ Put anything in the mouth
- ✗ Restrain the person
- ✗ Tilt or tip the wheelchair

CALL 911 IF:

- ◇ Injury has occurred
- ◇ There is liquid/food/vomit in mouth
- ◇ Seizure occurs in water
- ◇ Another seizure follows
- ◇ Shaking of seizure lasts more than 5 minutes
- ◇ Breathing is difficult after the seizure

This is not medical advice nor an exhaustive list of responses to seizures. This is a guide to help you consider your response to seizures. If you are in any doubt about what to do, do not hesitate to call 911.



Epilepsy Foundation North Central Illinois, Iowa and Nebraska
www.epilepsyheartland.org 1-800-221-2689

Developed by L. Neece-Baltaro, EFNCIL, with funding from Health Resources and Services Administration's Maternal and Child Health Bureau for Project Access—Nebraska-Telehealth for Children with Epilepsy Grant # H98MC20270.

Sports Guidelines for Students with Epilepsy

Participation in group activities is a part of childhood that fosters a sense of belonging, self-esteem and independence, as well as the development of interpersonal skills. Because epilepsy affects each person differently, the approach must be individualized, and guided by common sense, with a goal to balance safety with opportunities to engage fully in life activities. Restriction and isolation foster low self-esteem and emphasize the disability. Children and youth with epilepsy should be encouraged to participate in group and competitive sports to the extent that it is safe. The benefits of engaging in group activities and sports are extremely valuable, and the risks of participation must be serious to warrant prohibiting a child from joining group activities.

In the City of Rochester, New York, Dr. Cynthia Devore, the Medical Director of the Rochester City Schools, approached a child neurologist, Dr. Margaret McBride in the late 1990's to help develop guidelines for schools to assist their students with epilepsy who want to participate in school sports. The University of Rochester Medical Center (URMC), Division of Child Neurology recently updated and modified these guidelines as part of its ongoing efforts to make seizure safety goals practical, clear, and consistent (TOOL 14).

Tool 14: Guidelines for Allowing Children with Seizures/Epilepsy to Participate in School Activities

Seizure Risk Classification	
Children with seizures meeting very low risk do not need to be on the medical alert list, but all others should be	Each student should be judged on an individual basis in conjunction with their neurologist when unclear.
Very Low Risk No seizures for over 2 years either on or off medication	No Restrictions
Low risk No seizures in past 1 year on medication No seizures in past 1 year off medication Seizures only during sleep Seizures that do not cause loss of consciousness Seizures that do not involve loss of body control	No Restrictions Allowed to drive. Allowed to operate machinery Allowed to participate in all school activities without special accommodation or restrictions, including heights, with normal adult supervision ratios as offered by the school. Allowed to swim with normal student to life guard ratios of no more than 15:1
Medium risk At least one seizure in the past 1 year, but fewer than 1 per month Seizures while awake Seizures with loss of consciousness Seizures with loss of body control and at least one such seizure in preceding one year but fewer than one month.	Restrictions Allowed to swim with certified lifeguard buddy and adult supervision; ratio of 10:1. Allowed to lift weights with 1:1 spotter or power-lifting with 1:2 spotters Allowed to participate in contact sports only with permission of neurologist. Allowed to operate open/heavy machinery with potential injury (i.e. table saws, etc.) on with a note from the child's neurologist and adult supervision and a buddy Not allowed to be at heights Not allowed to drive Not allowed to participate in archery, riflery, fencing or wrestling
High risk Seizures occurring 1 per month or more frequent Seizures while awake Seizures with loss of body control	Restrictions as above, plus the following additions or alterations Strong recommendation to involve a child neurologist if none involved Either no swimming or swimming only with an adult lifeguard in pool with child as 1:1. Not allowed to do weight lifting or use heavy equipment. Allowed only to do floor work (nothing at heights) Not allowed to participate in contact or collision sports Should use protective headgear if prescribed by physician or requested by parent
Extremely High risk Seizures occurring daily or more often Seizures with loss of consciousness Seizures with loss of body control	All Restrictions as above and consult with treating child neurologist if there are questions



Left to right: Franny Lerner, MPH; Henry Munoz, Linda Blatt, R.N., CC at the Project Access Advisory Committee meeting held in Arlington, VA (September 2012)

Organizing Community-Based Services for Family Accessibility

Timely access to pediatric subspecialists and pediatric surgical specialty care is becoming increasingly difficult for our nation's children and families, for the following reasons:

1. The supply of pediatric subspecialists is inadequate to meet the health needs of children.
2. Most pediatric sub-specialists practice in academic settings, leaving many rural areas and regions at some distance from academic centers without any pediatric subspecialists.
3. Even in regions with pediatric subspecialists, families often face long wait times to obtain an appointment with a pediatric subspecialist.
4. Fewer medical residents are choosing careers in pediatric subspecialties, while the existing workforce continues to age.
5. As the pediatric workforce continues to shrink, demand for pediatric subspecialty care is on the rise.¹¹

For children with epilepsy, there are particular challenges related to the unique preparation required of specialists in pediatric neurology. Pediatric neurologists who complete this preparation are certified by the American Board of Psychiatry and Neurology (ABPN) as having specific qualification in Child Neurology. Many child neurologists also obtain Board Certification in Pediatrics through the American Board of Pediatrics (ABP), which requires two years of training in general pediatrics. Like other subspecialists, these providers are concentrated in academic medical centers but according to the directory of the National Association of Children's Hospitals and Related Institutions (NACHRI), only 28 states have a pediatric hospital with a special program in neurodevelopmental disabilities of the nervous system and brain.¹² The Council of Pediatric Subspecialties estimates that the number of child neurologists in the US is at least 20% below the national needs, and this may be a conservative estimate.¹³ Furthermore, only 27% of hospital referral regions have a specialist in neurodevelopmental disabilities, resulting in a ratio of 570,784 children per physician, on average.¹⁴ Similarly, 33% of organizations are recruiting for pediatric neurologists, and 100% of them report medium to high difficulty, as indicated by the fact that they have been actively recruiting for 75% of positions for at least 6 months.¹⁵

11 American Academy of Pediatrics. Fact Sheet. At <http://www.aap.org/en-us/about-the-aap/departments-and-divisions/departments-of-education/Documents/Sec5203FactSheet.pdf> Accessed July 22, 2013

12 National Association of Children's Hospitals and Related Institutions. Hospital Directory. Retrieved on September 20, 2013, from http://www.childrenshospitals.net/AM/Template.cfm?Section=Hospital_Directory1&Template=/CustomSource/HospitalProfiles/HospitalProfileResultNew.cfm.

13 Council of Pediatric Subspecialties. Retrieved September 20, 2013, from <http://www.pedsubs.org/subdes/neurology.cfm>.

14 Mayer, ML. Are we there yet? Distance to care and relative supply among pediatric medical subspecialties. *Pediatrics* 2006; 118 (6): 2313-2321.

15 American Academy of Pediatrics. Pediatric Workforce Shortages: Policy and Advocacy Challenges. Accessed at <http://www.aap.org/en-us/about-the-aap/departments-and-divisions/departments-of-education/Pages/Division-of-Workforce-and-Medical-Education-Policy.aspx?nfstatus=401&nftoken=00000000-0000-0000-0000-000000000000&nftstatusdescription=ERROR%3a+No+local+token> On July 22, 2013.

In 2010, 61% of hospitals reported waits for neurology appointments over the two-week benchmark, with wait times of 47.6 business days, or 9.5 weeks.⁶ This finding was reinforced by a survey of primary care providers, which found that 66.7% of primary care pediatricians reported too few pediatric neurologists to meet the needs of their patients (66.1% in non-rural areas, and 70.7% in rural areas), raising significant concerns about the adequacy of children's access to pediatric subspecialists, especially in rural communities.¹⁶

Using Technology to Improve Accessibility of Services

Access to quality care may be compromised when pediatric subspecialists are not available. In addition, in some cases families must travel to a distant center for care, or may need to relocate to another community in order for their child to receive needed services.⁶ Technologies such as telemedicine present opportunities for increasing access to care because new technologies may make it easier for families to be seen by their specialist provider, and also leads to cost/time savings and increased family and provider satisfaction.^{17, 18}

Two Project Access teams focused on reducing barriers to services and supports through the use of technology. In each of the approaches described below, children and youth with epilepsy and their families were critical to the development and successful implementation of strategies designed to provide accessible, coordinated, ongoing, and comprehensive care.

Using Telemedicine to Increase Access to Specialty Medical Services

The Michigan-based Project Access Team was a partnership of the Michigan Department of Community Health in Lansing and the Epilepsy Foundation of Michigan in Southfield. The *Awareness and Access to Care for Children and Youth with Epilepsy Project* aimed to:

1. improve access to care for children and youth with epilepsy, and
2. develop an interoperable and sustainable statewide network of telemedicine sites in rural areas that connect to the three largest children's hospitals in Michigan.

Although Michigan telemedicine services are not yet reimbursed through commercial payers, Medicaid and Children's Special Health Care Services, Division of the Michigan Department of Community Health and Medicaid reimburse for these services. Implementing telemedicine to increase access to services has the additional benefits of saving transportation and lodging costs for families who would otherwise need to travel significant distances to see a specialist, as well as travel and time savings when physicians do not need to travel to rural areas to see patients. Parents and youth have played an important role in the successful telemedicine implementation in Michigan.

16 Pletcher, BA, Rimsza, ME, Cull, WL, Shipman, SA, Shugerman, RP, and O'Connor, KG. Primary care pediatricians' satisfaction with subspecialty care, perceived supply, and barriers to care. *Journal of Pediatrics*. 2010 156: 1011-1015.

17 Bingham, E., & Patterson, V. (2007). A telemedicine-enabled nurse-led epilepsy service is acceptable and sustainable. *Journal of Telemedicine and Telecare*, 13 (suppl 3), 19-21.

18 Whitten, P., Holtz, B., & LaPlante, C. (2010). Telemedicine: What have we learned? *Applied Clinical Informatics*, 1(2), 132-141.

The Michigan team faced the challenge of initiating a new technology that some providers were reluctant to adapt into their practices. Applying a multi-component approach, this team established a formal infrastructure to build capacity for and support for family engagement in advancing access to services through telemedicine that connects each site with the statewide Family Support Network of Michigan. The Family Center is a parent-directed section of the Children's Special Health Care Services Program (CSHCS), Michigan Department of Community Health established to 1) bring consumer input into CSHCS program and policy development, 2) establish a community-based, parent-to-parent support network for families of children with special health needs, and 3) facilitate parent/professional collaboration at all levels of health care.

The Family Center for Children and Youth with Special Health Care Needs (The Family Center), Michigan Department of Community Health employed a parent consultant to model the family centered approach by partnering with medical professionals and others. The parent consultant provided trainings for families local to the telemedicine sites to develop capacity as Parent Partners. The Family Center integrated consumer perspective into the development of family-centered telemedicine programs by engaging parent and youth in the process of developing the sites. The parent consultant developed and delivered P2P Trainings to support capacity for Parent Partners to serve as resources, advocates, and supports for families of children with epilepsy (See TOOL 15 and also TOOL 3). Youth Partners were also enlisted to support this initiative. Youth Partners are

Telehealth refers to a broad use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration. Technologies include videoconferencing, the internet, store-and-forward imaging, streaming media, and terrestrial and wireless communications.

Telemedicine falls within telehealth, but focuses more specifically on the use of electronic communication and information technologies to provide or support clinical care at a distance.

HRSA Office for the Advancement of Telehealth ➤

Tool 15: Topics Included in Parent to Parent Training

Parent to Parent Training Topics ➤

1. Leadership training
2. Parent to Parent Support training
3. Effective Communication Tools/Techniques
4. Confidentiality and HIPAA Guidelines/Training
5. Resources for Families
6. Transition Training
7. Sustainability

- P2P USA ➤

young adults between the ages of 18-26 years old with a diagnosis of epilepsy. Working with the project team and the parent consultant, the Youth Partner engages other youth within the local telemedicine office practice and within the local community, serving as a resource, advocate, and peer support for youth with epilepsy and other special health care needs. Standardized job descriptions for each of these roles are noted in TOOL 16 and Appendices E through F).

The Michigan Department of Community Health plans to expand the scope of services through telehealth technology to include other neurology services as well as behavioral, rheumatology, and obesity health care for children and youth with special health care needs across the state.

Social Media as a Means for Social Support and Increasing Awareness of Available Services

The Monroe-Meyer Institute at the University of Nebraska Medical Center utilized social media through Facebook, Twitter, and blogs to conduct educational outreach, and to establish a support network for families who would otherwise be isolated. Nebraska's social media outreach began with Jennifer Koehlmoos' story. As the mother of a toddler diagnosed with epilepsy at only 14 months with no previous family history, Jennifer longed to find people with whom she could connect. She felt isolated in her rural Nebraska town of approximately 3,700 people. At first there were just a few mothers across the state with whom she connected via the Epilepsy Foundation. Two years later, these same women, along with the other parents and children and youth with epilepsy who have joined them, have become not just friends for each other but confidants and a "family" of people who deeply understand each other's challenges and emotions. They report that they are there for each other whenever needed—when times get tough, when they feel that their questions aren't being answered by providers, and when their child's future looks bleak.

While there have been significant obstacles to bringing telehealth to all the rural Nebraska children with epilepsy who might benefit from it, Nebraska's Project Access has significantly impacted a number of rural Nebraska families through its online "Touched by Epilepsy Support Group" via Facebook and Twitter. The "Touched by Epilepsy Support Group", launched shortly after Jennifer Koehlmoos became the Parent Partner for the Nebraska team, utilizes social

Tool 16: Job Descriptions for Parent/Youth Telemedicine Partners & Telemedicine Visit Evaluation Resources

Resources

Appendix E: Parent Consultant Job Description
Appendix F: Telemedicine Parent Partner Job Description
Appendix G: Telemedicine Youth Partner Job Description
Appendix H: Telemedicine Visit- Parent Evaluation

Tool 17: Parent Partner Role Description for the Nebraska Project Access Team

1. Conduct in-person, on-site presentations for large-scale, high profile organizations (i.e. school nurses, people who conduct early childhood developmental evaluations) most preferably at their regional conferences. This provides a “human face” and exposure to the telehealth effort here in Nebraska.
2. Establish a “remote” presence via internet-based applications
 - a. One-to-one via traditional resources (i.e. telephone calls, emails)
 - b. Remote access to clients via face-to-face systems (i.e. Adobe Connect Pro) for one-on-one (answering questions) or one-to-many such as webinars with featured speakers
3. Help establish and monitor for content (on a daily basis) a youth online support system for children between the ages of 11 – 19. (e.g., Facebook, Wiki).
4. Act as liaison with Epilepsy Foundation North/Central Illinois, Iowa, Nebraska and Epilepsy Foundation National Office in terms of reporting project events, updates and progress on various project activities.
5. Conduct outreach campaigns using the contacts database as potential audience. These campaigns would address particular topics of interest (i.e. epilepsy in young children).
6. Extend social media to include Twitter capability.
7. Continue to contribute to her blog targeted towards young mothers; ensuring RSS capability, ability to field and share comments, and posts to Twitter.
8. Contribute to the upcoming epilepsynebraska.com website; including videos, articles from other websites that she comes across.
9. Through blog and epilepsynebraska.com website, maintain a “listening post” so that new products, groups, information can be readily passed along to her readers. Maintain a presence for telehealth, Epilepsy Foundation North/Central Illinois, Iowa, Nebraska and University of Nebraska Medical Center’s telehealth program.
10. Participate in product development (programs, ads, educational efforts, fact sheets, surveys) for Project Access, including developing, researching and editing for unique content presentation.

media to bring people together across the vast and sparsely populated state of Nebraska. The private group, with membership by invitation only, was established on Facebook (See TOOL 18 for pros and cons of establishing a private support group on Facebook). While the emphasis is on parents of children with epilepsy, members include family members of people with epilepsy who may be young, old, newly diagnosed, or veterans of the epilepsy “battle”, or people with epilepsy themselves. TOOL 17 describes the Parent Partner role for the Nebraska team, with specific guidelines for a parent role in extending the use of technology to support families of children with epilepsy.

Tool 18: Considerations and Resource for Establishing a Private Support Group on Facebook


Establishing a Private Support Group on Facebook

Pros:

- Allows for management of new members
- Allows for ensuring that postings are appropriate
- Allows for protection of family privacy

Cons:

- Difficult to promote/market
- Challenging to increase membership
- Requires resources to manage

Facebook <https://www.facebook.com/help/162866443847527/> 

Improving Provider Capacity through Neurology Outreach and Education Programs

In addition, children and youth with epilepsy are more likely than those without to have additional medical, psychiatric and cognitive conditions - alone or in combination - adding another layer of challenges to meeting their health care needs.^{19, 20, 21}

This has important implications for diagnosis, treatment and quality of life, particularly because many non-specialized providers lack experience in working with the complexity that characterizes the health and social needs of this population.²²

The next section provides some resources for increasing capacity of providers to provide services for children and youth with epilepsy through in-person community outreach, the development of web-based training for primary care providers, and a model of co-managing care of children and youth with controlled epilepsy.

19 Seidenberg, M., Pulsipher, D. T., & Hermann, B. (2009). Association of Epilepsy and Comorbid Conditions, *Future Neurology* (Vol. 4, pp. 663-688).

20 Tellez-Zenteno, J. F., Patten, S. B., Jetté, N., Williams, J., & Wiebe, S. (2007). Psychiatric comorbidity in epilepsy: A population-based analysis. *Epilepsia*, 48(12), 2336-2344.

21 Institute of Medicine. (2012). *Epilepsy across the spectrum: Promoting health and understanding*. Retrieved September 20, 2013, from <http://www.iom.edu/Reports/2012/Epilepsy-Across-the-Spectrum.aspx>

22 Seidenberg, M., Pulsipher, D. T., & Hermann, B. (2009). Association of Epilepsy and Comorbid Conditions, *Future Neurology* (Vol. 4, pp. 663-688).

Face-to-Face Outreach

FACETS of Epilepsy Care in New Hampshire (NH), a partnership between NH Family Voices and the NH Special Medical Services Program, coordinated outreach education for community providers, educators and families to raise awareness about the latest epilepsy treatments. Regional outreach events for parents and community providers as well as primary care providers included smaller group trainings as well as larger symposia on topics such as Psychotropic Medications and Epilepsy, Emerging Research, and Recommendations of the 2012 Institute of Medicine Report. FACETS engaged primary care providers, neurologists, Title V staff and families and youth partners in collaborative planning for improving the system of services in NH for children and youth with epilepsy and their families. Other groups that benefitted from NH outreach and education included Head Start staff, early educators, day care providers. Tested tips for coordinating outreach education for community providers and families are outlined in TOOL 19.

Web-Based Training

A partnership between the Children's Hospital of Pittsburgh, the Epilepsy Foundation of Western/Central Pennsylvania, and the Epilepsy Foundation of Eastern Pennsylvania, developed a web-based training, *Epilepsy 101 for Primary Care Practitioners* (TOOL 20), to increase awareness and skills related to providing services to children and youth with epilepsy.

“ When we were first diagnosed, we felt that the hospital and doctors gave us very little information or support. We were scared and confused. The Touched by Epilepsy Support Group made me feel less alone and like I wasn't the only one going through this. It was a great way for me to learn more about Epilepsy where I could ask any question and get answers from families who had been there. The Touched by Epilepsy Support Group helped us learn about seizure dogs and sleep monitors. It helped us understand that meds for epilepsy are complicated and there are no easy answers. I can't imagine being newly diagnosed and not having this group to lean on. Even now, when our situation has gotten much better, I still keep up with the group and feel like I have made some good friends-even though I have yet to meet any of them in person! I'm very grateful to have this support group and hope that it can help many more families! “

- Touched by Epilepsy Support Group Member

Tool 19: Tips for Coordinating Outreach Education for Community Providers and Families

Main Speaker: Enlist a speaker that will attract the audience, someone who blends technical and “lay person” language well, entertains and answers questions throughout presentation, and sets a comfortable, engaging tone.

Location: Choose a central location, with good access and parking.

Time: Choose a time that works for community providers AND families, such as between 5:30-8:00 pm, and provide food.

Outreach: Conduct outreach via early intervention, Head Start, school nurse listserv, Title V Program for CYSHCN, Family Voices affiliate, state and regional service delivery system for individuals with developmental disabilities and chronic illnesses; local Epilepsy Foundation, care coordinators within primary care practices; and previous attendees. In addition to advertising in traditional newspaper and poster formats, also use technology such as email and Facebook.

Materials: Share materials that support continued learning, such as communication tools (seizure action plans, seizure description tools, etc.). Provide a sign-up list for individuals seeking additional materials.

- FACETS of Epilepsy in New Hampshire Project Access Team

Tool 20: Web-Based Training - Epilepsy 101 for Primary Care Providers

The Pennsylvania Team partnered with Dr. Miya Asato, a neurodevelopmental specialist at Children’s Hospital of Pittsburgh, to reach out to primary care practitioners with a web-based “Epilepsy 101” training to increase awareness and skills related to providing services to children and youth with epilepsy.

📌 Epilepsy 101 for Primary Care Practitioners

Dr. Miya Asato is Assistant Professor of Pediatrics & Psychiatry Program Director, Neurodevelopmental Disabilities Residency Division of Child Neurology Children’s Hospital of Pittsburgh. Her presentation provides a basic introduction to epilepsy, including diagnosis, treatment and opportunities for patient co-management.

Primary Provider-Specialist Co-Management Model

Another strategy to improve access to community-based care was developed and implemented in Mississippi, a rural state with critically limited medical resources. Many children and youth with epilepsy must travel hundreds of miles to visit a specialist in the neurology clinic at the tertiary care center for the state, even though their epilepsy is well controlled and their care is routine. The Mississippi Epilepsy Care Improvement Coalition developed and implemented an epilepsy co-management model that offers children and youth with well-controlled epilepsy the option of primary physician care in their community for routine monitoring of their condition. Mississippi is a rural state with limited medical resources. This model allows the few epilepsy specialists based at the state's tertiary care center to provide treatment for children and youth with more demanding conditions.

➤ **The Mississippi Epilepsy Care Improvement Coalition IMPLEMENTATION MANUAL** outlines the steps taken by the Mississippi project to establish a co-management system of care for children with well controlled epilepsy. It reflects on the Mississippi pilot program's lessons learned and includes resources and tools developed to support this project so that other states facing similar challenges with shortages of specialty care physicians will be able to develop their own system of co-management care.

Summary

The tools provided here were developed by families and providers collaborating to improve the system of care for children and youth with epilepsy. This toolkit was designed to provide practical advice and guidance to families, educators and caregivers working to improve systems of care for children and youth with epilepsy and other special health care needs. We hope that sharing this information will promote the spread and sustainability of best or better practices that formalize family engagement in the process of system improvement, and promote care coordination across settings.

Appendix A: LEAP Project Description



**EPILEPSY
FOUNDATION®
WESTERN/CENTRAL PENNSYLVANIA**

Not another moment lost to seizures 1501 Reedsdale Street, Suite 3002, Pittsburgh PA 15233

L.E.A.P. to Understanding – The Local Epilepsy Awareness Project

As part of a federal Health Resources and Services Administration grant, the Epilepsy Foundation of Western/Central Pennsylvania, in collaboration with the Epilepsy Foundation of Eastern Pennsylvania, is partnering with the Bureau of Family Health, PA Department of Health in a *rural* outreach/community engagement effort to better understand the needs and service gaps of children and youth with epilepsy and their families.

PROJECT PURPOSE: Establish regional and a statewide strategy to increase awareness and understanding of epilepsy and increase access to care for children and youth with epilepsy in more rural, medically underserved areas of the state. The project will also support the development of regional and statewide communities of practice which will be designed to fulfill four goals:

1. **Epilepsy Awareness:** Make available an on-going vehicle to provide needed epilepsy awareness and first aid information and training to a variety of audiences,
2. **Medical Access:** Assist children, youth and families in accessing needed medical services,
3. **Community Supports and Services:** Identify and develop a mechanism to link children, youth and families with needed local community supports and services, and
4. **Ongoing Needs Identification:** Identify needs and gaps in services of children and youth with epilepsy and their families.

Historically, a major challenge for the Epilepsy Foundation affiliates has been reaching and assisting families living in more isolated, rural areas of the state to help them access needed medical and community supports and services. Out of the Commonwealth's 67 counties, 48 (72%) are considered rural. It is estimated that 28% of the state's population lives in these rural counties. Of these residents, it is estimated that at least 35,567 (1%) have epilepsy. Twenty-five percent (25%) of rural residents are age 19 or younger. Of those children and youth approximately 9,000 have epilepsy. Many of these children and youth with special health care needs (CYSHCN) also have additional health conditions/disabilities including autism, cerebral palsy, intellectual disabilities and many other critical health conditions.

Local learning communities or communities of practice (CoPs) will be developed in each of the six PA Department of Health regions through existing Bureau of Family Health (BFH) Special Kids Network System of Care meetings. These meetings are regularly convened to focus on resolving system and special health care issues and cases in each health district. The CoPs will invite a number of stakeholders together including: parents, youth, primary care, neurology, education, county and other community providers, to discuss local/regional service gaps, concerns, and needs related to epilepsy as well as those of children with other special healthcare needs. The CoPs will be facilitated by the Special Kids Network System of Care Regional Coordinators and parents of children/youth with epilepsy. The dialog will be structured around the six priorities previously identified during earlier BFH community engagement efforts. These include: cultural competence, care coordination, access to information and resources, family and youth involvement in planning, pediatric medical home and youth needs for independent living. Ultimately, a final report of the recommendations, strategies and priorities identified through the CoPs will be submitted to the PA DOH Title V program, the Epilepsy Foundations and local communities. Finally, it is anticipated that the six regional Communities of Practice will provide on-going opportunities for information gathering, problem solving and needs identification.

For additional information please contact: Rick Boyle, Special Projects Director, rboyle@efwp.org
PHONE: 412-322-5880 • 1 (800) 361-5885 • FAX: 412-322-7885 • TDD EOP/AUX AID 1-800-855-2882 •
www.efwp.org

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Appendix B: Leap Facilitator Guidelines



**EPILEPSY
FOUNDATION®
WESTERN/CENTRAL PENNSYLVANIA**

Not another moment lost to seizures 1501 Reedsdale Street, Suite 3002, Pittsburgh PA 15233

As part of a federal Health Resources and Services Administration grant, the Epilepsy Foundation of Western/Central Pennsylvania, in collaboration with the Epilepsy Foundation of Eastern Pennsylvania, is partnering with the Bureau of Family Health, PA Department of Health in a *rural* outreach/community engagement effort to better understand the needs and service gaps of children and youth with epilepsy and their families. This will be accomplished by holding information gathering (listening sessions) meetings in each of the six Department of Health Community Health Districts. The meetings will be facilitated by parent-led teams consisting of the Bureau of Family Health, Special Kids Network System of Care Regional Coordinators and parents of children/youth with epilepsy. The findings of the meetings will be synthesized into a final report of recommendations and strategies to increase awareness and understanding of epilepsy and increase access to care for children and youth with epilepsy in more rural, medically underserved areas of the state.

In an effort to recruit potential parent facilitators, the following qualifications and roles have been developed. The candidate for parent facilitator must:

- Be a parent of a child, youth or young adult who is being treated or has been treated for epilepsy/seizure disorder
- Be able to represent and share the concerns and issues of other children, youth and families affected by epilepsy as well as their own.
- Be able to see the “big picture” of the challenge of accessing needed medical and community supports and services
- Be willing to work as a team player
- Be able to develop and maintain positive relationships with other family members, youth and community members
- Have good written and verbal communication skills and is comfortable speaking in public
- Be willing to participate in group facilitation training and assist in facilitating information gathering meetings at the local and regional level
- Be willing to travel to and help facilitate at least two information gathering meetings
- Be willing to participate in project conference calls to:
 - assist in identifying other community stakeholders who could participate in the epilepsy information gathering process as well as issues pertaining to children/youth with other special healthcare needs
 - Provide feedback and suggestions to inform a regional and statewide strategy
 - Follow up on meetings and project activities

Timeline for project and hours expected

- Project will begin March 2013 and end September 2013
- The time commitment is expected to be approximately 4 hours per month

Compensation/Reimbursement

- Parent facilitators will be provided with a small stipend and reimbursement for travel, hotel and child care expenses

For additional information please contact: Rick Boyle, Special Projects Director, rboyle@efwp.org

PHONE: 412-322-5880 • 1 (800) 361-5885 • FAX: 412-322-7885 • TDD EOP/AUX AID 1-800-855-2882 • www.efwp.org
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Appendix C: LEAP To Understanding Training Agenda



L.E.A.P. to Understanding – The Local Epilepsy Awareness Project

PROCESS PLAN

Summer 2013



Session Objectives:

1. To deepen our connections as a community of parents of children with epilepsy.
2. To identify our community needs, existent services, and service gaps.
3. To inspire us to move forward as a local Community of Practice.

Process Plan:

Time	Agenda Item	Process	Materials * Equipment
5:00 – 5:30	Set-up	Set-up <ul style="list-style-type: none"> □ Arrange chairs/tables in horseshoe that will optimize view of the screen <u>and</u> a long blank wall for the wall display. □ Set up technology (screen, projector, music). □ Play the <i>Did you know...</i> PowerPoint on continuous loop. □ Set up refreshments. □ Put out agendas, markers, post-its, and nametags. □ Set up chart stand and chart pad. 	<ul style="list-style-type: none"> □ Laptop □ Projector □ Screen □ PowerPoint (PPT) □ Music (optional) □ Horseshoe □ Agendas & Handouts □ Chart stand □ Chart pad □ Large post-its (5"x7") □ Markers/sharpies □ Nametags □ Refreshments □ Registration table
5:30 – 6:00 By 5:30, be free from set-	Host	<ul style="list-style-type: none"> □ Help people feel welcome! □ Introduce parents to each other. □ Share about yourself. □ Invite people to have refreshments. 	<ul style="list-style-type: none"> □ Refreshments
Time	Agenda Item	Process	Materials * Equipment
up so you can host!		<ul style="list-style-type: none"> □ Try to learn names and details. 	
6:00 – 6:20	Welcome <ul style="list-style-type: none"> □ Agenda Overview □ Introductions <ul style="list-style-type: none"> ■ Briefly introduce yourself ■ Share a support or service that you value 	Getting started: <ul style="list-style-type: none"> □ Around 5:55, stop the <i>Did you know...</i> loop. □ Display the welcome slide. □ Ask people to settle into seats. Opening <ul style="list-style-type: none"> □ Project LEAP purpose & goals □ Session objectives □ Norm: All voices & all ideas! Introductions <ul style="list-style-type: none"> □ <u>Triggering Question</u>: <i>What is one support or service for your child or family that you value?</i> □ <u>Directions</u>: <ul style="list-style-type: none"> □ Write one service or support on a post-it using marker. □ Briefly introduce yourself and share a support or service that you value. □ Place post-its in columns or randomly on the wall while people introduce themselves. 	<ul style="list-style-type: none"> □ PPT □ Agenda □ Markers/sharpies □ Large post-its (5"x7")
6:20 – 7:10 6:20 – 6:30 Brainstorm	Needs in our Community <ul style="list-style-type: none"> □ What we need 	Brainstorm Needs (10 minutes) <ul style="list-style-type: none"> □ <u>Triggering Question</u>: <i>What are the needs of children and youth with epilepsy and their families in our community?</i> □ <u>Response parameters</u>: <ul style="list-style-type: none"> □ Work with one or two other persons. □ Describe the need or problem (not the solution). □ Write whole <u>short</u> sentences. □ Write one idea per post-it. □ Identify as many as you wish. □ All ideas go! 	<ul style="list-style-type: none"> □ PPT □ Markers/sharpies □ Large post-its (5"x7")

Time	Agenda Item	Process	Materials * Equipment
		Set-up Classification While people brainstorm, set up the display wall. <ul style="list-style-type: none"> <input type="checkbox"/> Across the top of the display wall, hang the seven column headers (the five DoH priorities plus "other"). <input type="checkbox"/> Down the left end of the display wall, hang the three row headers (needs, existent services, service gaps). <input type="checkbox"/> In the existent services row, sort the valued services (that participants identified during the introductions activity) under the priorities headers where they best fit. <input type="checkbox"/> [Note: Hold "Pediatric Medical Home" and only use if participants identify needs that fit.] 	<input type="checkbox"/> Column Headers (on post-its) <ul style="list-style-type: none"> • Cultural Competence • Service Coordination • Access to Information & Resources • Family & Youth Involvement in Planning • Youth Needs for Independent Living • Other • [Pediatric Medical Home] <input type="checkbox"/> Row Headers (on post-its) <ul style="list-style-type: none"> • Needs • Existent Services • Service Gaps
6:30 – 7:00 Sort Weed & Add		Sort Needs (15 minutes) <ul style="list-style-type: none"> <input type="checkbox"/> Say, <i>While you were brainstorming I set up a preliminary framework for sorting our ideas. I sorted your post-its from the beginning of the day as "existent services." You can move them if I put them in the wrong places.</i> <input type="checkbox"/> <i>These areas across the top are priorities that were identified for the Pennsylvania Department of Health by a broad set of stakeholders.</i> <input type="checkbox"/> Briefly reference "What Guides Our (PDH) Work." (Hold Pediatric Medical Home and only use if participants identify a related need.) <input type="checkbox"/> <i>The results of our meeting will go to the Epilepsy Foundation (both Western/Central and Eastern Offices) and the Pennsylvania Department of Health. It may be helpful to have epilepsy-specific needs aligned to the</i> 	<input type="checkbox"/> Markers/sharpeners <input type="checkbox"/> Large post-its (5"x7") <input type="checkbox"/> "What Guides our Work" PDH Handout <input type="checkbox"/> Dot stickers

Time	Agenda Item	Process	Materials * Equipment
		broader DoH priorities. <ul style="list-style-type: none"> <input type="checkbox"/> Say, <i>Let's see if the needs that you identified fit in these areas. We can add other headers if these headers don't work.</i> <input type="checkbox"/> <i>Also, if you wrote the need statement more as a "needed service", you might want to post it in the "service gaps" row.</i> <p><i>Options ... depending on size of group.</i></p> <ul style="list-style-type: none"> <input type="checkbox"/> If a small enough group, collect ideas one-by-one in each category. Have the author of the idea discuss the need as you collect the post-it and place it on the framework on the wall. <input type="checkbox"/> If a large group, get everyone up and sorting side-by-side. After all ideas are sorted, sample a few ideas to discuss. Weed & Add Needs (15 minutes) <ul style="list-style-type: none"> <input type="checkbox"/> Say, <i>Let's clean up the sort by weeding out redundancies and adding any missing need statements. Feel free to move any post-its that don't seem to be in the right place.</i> <input type="checkbox"/> <i>Please work in small groups to stack ideas that are exactly the same and to write additional post-its for missing needs, like this. (Stack an example.)</i> <input type="checkbox"/> Try to only add other headers, if needs definitely won't fit under PDH priorities. 	
7:00 – 7:30	Existent Services and Service Gaps <ul style="list-style-type: none"> <input type="checkbox"/> What we have <input type="checkbox"/> What we lack 	Existent Services & Service Gaps (15 minutes) <ul style="list-style-type: none"> <input type="checkbox"/> <i>Given the needs that you have identified, what are other existent services and service gaps in our community?</i> <input type="checkbox"/> <i>Write one idea per post it.</i> Prioritize Needs & Service Gaps <ul style="list-style-type: none"> <input type="checkbox"/> <i>What are the six greatest needs (or service gaps) in our community?</i> 	<input type="checkbox"/> PPT <input type="checkbox"/> Markers/sharpeners <input type="checkbox"/> Large post-its (5"x7") <input type="checkbox"/> Dot stickers

Time	Agenda Item	Process	Materials * Equipment
		<input type="checkbox"/> Place dot stickers on six different need statements (or service gaps). <input type="checkbox"/> Summarize greatest needs (statements with most dots).	
7:30 – 7:40	Break	<input type="checkbox"/>	<input type="checkbox"/>
7:40 – 8:20	Inspiring Action in Our Community <ul style="list-style-type: none"> <input type="checkbox"/> How we might move to action 	Move to action (15 minutes) <input type="checkbox"/> Community Conversations reports will go to: <ul style="list-style-type: none"> Each Community Department of Health Epilepsy Foundation <input type="checkbox"/> Special Kids Network (Department of Health) can provide: <ul style="list-style-type: none"> Family gatherings – intimate gatherings of families Special Kids Networks meetings – if issues are identified that are appropriate to brainstorm and focus resolution Bi-annual PYPF meetings – opportunities for families to continue to have a voice and make connections <input type="checkbox"/> The Epilepsy Foundation could provide: <ul style="list-style-type: none"> Meeting summary Resources and information Support for the group to come back together. The support of the regional coordinator as a facilitator or resource person. <input type="checkbox"/> Invite participants to express interest on Community of Practice interest form.	<input type="checkbox"/> Chart paper <input type="checkbox"/> Markers <input type="checkbox"/> Masking tape

Time	Agenda Item	Process	Materials * Equipment
		Option: Next Steps: <input type="checkbox"/> Facilitator: If individuals or the group make commitments, chart as next step statements that tell “who will do what by when.” <input type="checkbox"/> Option: Input next steps on Notes Template. Project on screen.	
8:20 – 8:30	Closing <ul style="list-style-type: none"> <input type="checkbox"/> Next Steps <input type="checkbox"/> Session Evaluation 	Next Steps: Reports <input type="checkbox"/> Option: Summarize the group’s next steps (from chart). Session Evaluation <input type="checkbox"/> Ask participants to complete evaluations. <input type="checkbox"/> Thank them for participating!	<input type="checkbox"/> Session Evaluation
	Follow-up	Report <input type="checkbox"/> Input needs, services, service gaps, actions, and next steps. <input type="checkbox"/> Forward to Rick Boyle at RBoyle@efwp.org	<input type="checkbox"/> Notes Template (electronic copy)

Appendix D: Sample LEAP to Understanding Training Evaluation

L.E.A.P. to Understanding – The Local Epilepsy Awareness Project

SESSION EVALUATION

May 29, 2013 * Nittany Lion Inn * Board Rooms 1 & 2
200 West Park Avenue, State College, PA 16803 * n = 20

1. How did we do on the session objectives?	Poor	Fair	Good	Excellent
• Overview the L.E.A.P. to Understanding: The Local Epilepsy Awareness Project.	1	2	3.45	4
• Deepen understanding of community of practice.	1	2	3.45	4
• Build facilitation skills to lead Community Conversations.	1	2	3.43	4
• Plan logistics for Community Conversations (participants, dates, locations, deliverables).	1	2	3.11	4
2. How do you rate the below variables?	Poor	Fair	Good	Excellent
• Opportunities for equitable participation	1	2	3.89	4
• Meeting process	1	2	3.22	4

3. Something that really worked well today was ...

Group Interaction

- Rhonda engaged everyone and made the training fun.
- Interaction with peers.
- Meeting with team throughout the day.
- Parent participation
- Having the opportunity to talk in small groups and sharing information.
- Being sat with our local area so we could brainstorm together and practice.
- Getting the conversation started.
- Communication/answers to questions

Practice

- The practice format
- Grouping teams to practice together.
- Practice, though brief.
- Enjoyed after lunch program when everything came together

Modeling

- Good examples and models.
- Modeling
- I think the training was very educational.
- Brainstorming

Thanks!

Appendix E: Parent Consultant for Pediatric Telemedicine Job Description



Job Description **Awareness and Access to Care for Children and Youth with Epilepsy** **Parent Consultant for Pediatric Telemedicine**

The position of the Parent Consultant regarding telemedicine expansion in Michigan is central to the development of the Awareness and Access to Care for Children and Youth with Epilepsy Project in Pediatric Epilepsy Telemedicine Practices. This position has been developed to model the family centered approach of partnering with medical professionals and others and to train families local to the telemedicine sites how to effectively become Parent Partners from two specific perspectives:

- 1) Co-create a development plan regarding partnering with the telemedicine site in establishing methods and practices from the family centered perspective
- 2) Developing confidence and expertise in parents and other family members. Also, effectively conveying a common message in utilizing effective methods by which to convey expectation and the value of practicing from a family centered approach. The family centered approach includes honoring, empowering and respecting the central role of the family as the constant in a child's life.

The Parent Consultant will be a parent of a child with special health care needs and will also be employed by the Family Center for Children and Youth with Special Health Care Needs, Michigan Department of Community Health.

The duties and roles of the Parent Consultant will include:

1. Assist in identifying and providing guidelines for choosing appropriate Parent Partners at each Telemedicine site.
2. Create a Development Plan for Parent Partners at each site.
3. Provide initial and ongoing training, education, outreach and support to empower Parent Partners to serve as the lead Parent Partner at each site.
4. Specific training to include Parent to Parent Support training through the Family Support Network of Michigan, Parent Leadership in State Government, Effective Communication Tools/Techniques, Confidentiality and HIPAA Guidelines/Training and Transition training.
5. Assist the Parent Partner in developing a needs assessment to address site needs to support families.
6. Support the Parent Partner in creating a Resource Sheet for families in the practice(s).
7. Seek input from Parent Partners in regards to systems changes specific to family centered care and epilepsy telemedicine as appropriate and other specific diseases/conditions.
8. Development of a Sustainability Plan for the Parent Partner program.

***The development of this document was fully funded by Grant Number H98MC20273, Access to Care for Children and Youth with Epilepsy, Maternal and Child Health Bureau, HRSA, DHHS.**

Appendix F: Parent Partner for Pediatric Telemedicine Sites Job Description



Awareness and Access to Care for Children and Youth with Epilepsy Parent Partner for Pediatric Telemedicine Sites

Job Description

The parent partner will engage other families both within the local telemedicine office practice and within the local community. The parent partner will use both professional and life experiences to provide parent support. The parent partner will be a resource, an advocate and support for families in similar situations. The parent partner will have excellent communication skills to guide other families. The parent partner will help to assess the needs of the families within the practice with the support of the state Parent Consultant and practice team. The parent partner will engage families through outreach methods as determined appropriate.

Qualifications:

1. Must have personal experience as a parent, guardian or caregiver of a child or youth with special health care needs.
2. Must maintain strict confidentiality as stated in HIPAA Guidelines.
3. Must be able to work as a member of the team.
4. Must have good written and verbal communication skills.
5. Must possess sensitivity to family culture, values and beliefs and operate from a family-centered strengths based perspective.
6. Must be willing to attend training as needed.
7. Must be knowledgeable about community resources.
8. Must have good organizational skills.

The duties and roles of the Parent Partner will include:

1. Assist and offer parent-to-parent support to parents and/or caregivers of children and youth with special health care needs.
2. Work with state Parent Consultant for Pediatric Telemedicine to create a development plan for the site.
3. Be knowledgeable about family-centered care, medical home, transition and cultural competency.
4. Develop a community resource database.
5. Seek input from families within the practice in regards to systems changes specific to family-centered care, epilepsy telemedicine and/or other conditions.
6. Connect parents to the community for support and resources.
7. Provide educational opportunities regarding topics of interest to families.
8. Attend training as needed to obtain current knowledge on HIPAA Guidelines

*The development of this document was fully funded by Grant Number H98MC20273, Access to Care for Children and Youth with Epilepsy, Maternal and Child Health Bureau, HRSA, DHHS.

Appendix G: Youth Partner for Pediatric Telemedicine Sites Job Description

Awareness and Access to Care for Children and Youth with Epilepsy Youth Partner for Pediatric Telemedicine Sites



Job Description

The youth partner is a young adult between the ages of 18-26 who has a diagnosis of epilepsy. The youth partner engages other youth within the local telemedicine office practice and within the local community. The youth partner uses appropriate professional skills and life experiences to provide peer support for youth with epilepsy and other special health care needs. The youth partner is a resource, an advocate and provides peer support for youth with epilepsy. The youth partner uses good communication skills to guide other youth. The youth partner assesses the needs of the youth within the practice with the support of the state Parent Consultant and practice team. The youth partner engages youth through accepted outreach methods.

Qualifications:

1. Must have experience working with youth
2. Must have good organizational skills
3. Must have good computer skills
4. Must have good skills related to social networking
5. Must maintain strict confidentiality as stated in HIPAA Guidelines
6. Must be able to take and follow direction
7. Must be able to work independently
8. Must have good verbal and written communication skills
9. Must possess sensitivity to family culture, values and beliefs and operate from a family-centered strengths based perspective
10. Must be willing to attend training as needed
11. Must be knowledgeable about community resources

The duties and roles of the Youth Partner includes:

1. Administer a closed Facebook page for youth with epilepsy in consultation with the state Parent consultant
2. Offer peer support to youth with epilepsy and other special health care needs
3. Partner with the telemedicine site and the state Parent Telemedicine Consultant to complete a youth needs assessment
4. Be knowledgeable about family-centered care, medical home, transition toward adulthood and cultural competency
5. Develop a community resource database
6. Support youth partnership within the practice regarding transition planning to adulthood and other identified issues of importance to youth at the site
7. Develop a community resource guide for youth in collaboration with the state Parent Consultant and the local site
8. Review materials and attend training as identified to obtain current knowledge on HIPAA Guidelines, family-centered medical home, cultural competency, and transition to adulthood

*The development of this document was fully funded by Grant Number H98MC20273, Access to Care for Children and Youth with Epilepsy, Maternal and Child Health Bureau, HRSA, DHHS.

Appendix H: Telemedicine Patient/Family Visit Evaluation Form



Pediatric Epilepsy Telemedicine Initiative* Patient/Family Visit Evaluation Form

Site: _____

Visit Date _____

Primary Care Provider: _____

Epileptologist/Neurologist: _____

This form is to be completed by patient/family at the end of each telemedicine visit.

1. This is the first time we have been seen as a patient by a telemedicine appointment.
Yes____ No____

2. If telemedicine was not available, I would have had to travel by:

My own car _____

Be driven by family/friend _____

Arranged for transportation through CSHCS _____

Unable to keep an appointment _____

3. The telemedicine appointment was able to meet my needs for epilepsy care today.

Strongly agree____ Agree____ Not sure____ Disagree____

4. Overall, I was satisfied with today's telemedicine appointment.

Strongly agree____ Agree____ Not Sure____ Disagree____

5. I will make another telemedicine appointment.

Yes____ No____

Comments or suggestions _____

6. My child's medication list was reviewed today.

Yes____ No____

7. My child has an epilepsy action plan.

Yes____ No____

8. I would like to learn more about epilepsy.

Yes____ No____

Comments or suggestions _____

9. I would like to be contacted personally about the telemedicine project.

Name _____ Contact phone or email. _____

*The development of this document was fully funded by Grant Number H98MC20273, Access to Care for Children and Youth with Epilepsy, Maternal and Child Health Bureau, HRSA, DHHS.

Appendix I: Pediatric Telemedicine Fact Sheet

Pediatric Telemedicine

IN MICHIGAN

Fact Sheet

Connecting You and Your Local Doctor to Your Child's Specialist

<http://pediatrictelemedicine.com>

Family Center 800-359-3722



Telemedicine Connects
You and Your Doctor to
Your Child's Specialist

What is Pediatric Telemedicine?

Pediatric Telemedicine is a new program developed to connect you and your child to your child's specialist from the convenience of your local doctor's office.

The purpose of the program is to increase local access to specialist care for children and youth. Telemedicine can also be useful for other medical and behavioral conditions.



Your Doctor's Office
is Your Medical Home

Using video conferencing technology, Pediatric Telemedicine provides access to pediatric specialists long distances away at select Michigan children's hospitals.

You, your child and your child's doctor will meet with your specialist from the comfort and convenience of your local doctor's office by using telemedicine technology.



Telemedicine connects you, your child and your doctor to your child's specialist.

What Organizations Developed Pediatric Telemedicine?

- Michigan Department of Community Health (MDCH)
- Children's Special Health Care Services (CSHCS)



There are Opportunities
for Education, Training
and Support From
Trained Professionals

Which Children's Hospitals are Participating?

- C S Mott Children's Hospital
University of Michigan
Ann Arbor, MI
- Children's Hospital of Michigan
Detroit, MI
- Helen DeVos Children's Hospital
Grand Rapids, MI



Youth and Teens will
Receive Support as
they Transition to
Adult Care

Pediatric Telemedicine

IN MICHIGAN

Fact Sheet

Connecting You and Your Local Doctor to Your Child's Specialist

<http://pediatrictelemedicine.com>

Family Center 800-359-3722



Telemedicine Connects
You and Your Doctor to
Your Child's Specialist

Telemedicine Saves Time and Money

With telemedicine technology, there's no need to take extended time from work or school to travel long distances to meet with your child's specialists.

You'll save money on lost time from work or school and also save on lost wages from work. You can also save on gas, hotel, and food expenses that you would normally have to pay out of pocket if you needed to drive out of town to meet with your child's specialist at select Michigan children's hospitals.



Your Doctor's Office
is Your Medical Home

Telemedicine Supports Your Family-Centered Medical Home

Your local doctor's office is your child's medical home. Your medical home helps you coordinate your child's care by connecting your local doctor's office to your child's specialist.



Your medical home will help you coordinate your child's care by connecting your local doctor's office to your child's specialist.



There are Opportunities
for Education, Training
and Support From
Trained Professionals

Coordinated Care

Your medical home will help you coordinate your child's care by connecting your local doctor's office to your child's specialist.

Opportunities for Education, Training and Support

Your family will have the opportunity to receive education, training and support from trained health care professionals from these organizations:

- Children's Special Health Care Services (CSHCS)
- The Family Center



Youth and Teens will
Receive Support as
they Transition to
Adult Care

Pediatric Telemedicine

IN MICHIGAN

Fact Sheet

Connecting You and Your Local Doctor to Your Child's Specialist

<http://pediatrictelemedicine.com>

Family Center 800-359-3722



Telemedicine Connects
You and Your Doctor to
Your Child's Specialist

Access to These Organizations Will Provide You With:

- Educational opportunities
- The latest information for your child's health care needs
- The support of trained professionals
- Support from a designated parent leader in your community, and other families that have children with similar health care needs



Your Doctor's Office
is Your Medical Home

Telemedicine Can Assist in Transition Planning to Adult Care

One important example of how telemedicine can assist in planning the transition from pediatric care to adult care is by supporting children, youth and teens to gradually take on more responsibility for their own care. In this program, children, youth and teens will be helped to learn to make the transitions to adult health care, education, work, and independence.



There are Opportunities
for Education, Training
and Support From
Trained Professionals

Who is Eligible to Participate in the Program?

Families that have children or youth with special health care needs living in select Michigan communities are eligible to participate in the program.

Contact your local health center to find out if they are participating in the program and if your child qualifies.



Youth and Teens will
Receive Support as
they Transition to
Adult Care



*Children and youth will be helped
to make transitions to adult life,
including adult health care, work,
and independence.*

Pediatric Telemedicine

IN MICHIGAN

Fact Sheet

Connecting You and Your Local Doctor to Your Child's Specialist

<http://pediatrictelemedicine.com>

Family Center 800-359-3722



Telemedicine Connects
You and Your Doctor to
Your Child's Specialist

Where Can I Get More Information?

Pediatric Telemedicine Initiative
<http://pediatrictelemedicine.com>

The Family Center

800-359-3722
cshcsfc@michigan.gov
www.michigan.gov/cshcs



Your Doctor's Office
is Your Medical Home

How Do We Get Involved?

Contact your doctor or local health center.
Ask if they participate in this telemedicine program.



*Contact your doctor or your
local health center. Find out if
your doctor participates in this
telemedicine program.*



There are Opportunities
for Education, Training
and Support From
Trained Professionals



Youth and Teens will
Receive Support as
they Transition to
Adult Care

Children's Special



Health Care Services

Funding provided by MDCH, CSHCS and HRSA Grant Number H98MC20273.

Appendix J: Seizure First Aid for Tonic-Clonic Seizures

Seizure First Aid for Tonic-Clonic Seizures

Cushion &
protect head



Turn on side,
Remove
harmful items



Loosen any
tight clothing



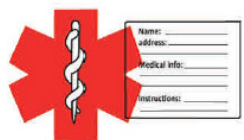
DON'T put
anything in
the mouth



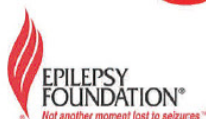
Time the
seizure



Check for a
medical I.D.
card



DON'T
restrain or
hold down



1-800-332-1000 or 1-800 221-2689

VNS: Device is usually implanted in left chest below collarbone.

Swipe magnet across skin above device for one second (counting one-one thousand). Swipe from mid-chest out toward shoulder. It can be swiped multiple times as long as there is a pause between swipes.

Wait 1 to 2 minutes (depending on student's seizure action plan) and if still seizing, swipe magnet again.

DO NOT hold the magnet over the device. Placing magnet for 6 seconds or more will turn device off!

CAUTION: Avoid overstimulation! If more than 4 hours of constant stimulation occurs, damage to the vagus nerve can develop.

Magnet works best if used early—as seizure starts or just before.

Rescue Medications

Diazepam Rectal Gel:

(See: www.diastat.com/how-to-administer.aspx)

Lay student on side, facing you.

Check dosage on side of barrel against student's prescribed dose.

Remove cap & check that locking pin is inside cap (not in nozzle).

Lubricate tip of administrator.

Bend student's upper leg to expose rectum.

THREE COUNTS OF THREE:

- > SLOWLY & gently insert tip into rectum while counting to 3.
- > SLOWLY count to 3 while pushing plunger until it stops
- > Hold rectum closed around tip and leave in rectum for count of 3.
- > SLOWLY remove administration tube and hold buttocks together to prevent leakage/loss of medication

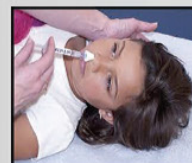
Buccal Lorazepam:

- 1 Lay student on side. Do not touch teeth, or force mouth open!
- 2 Wipe away excess saliva from mouth.
- 3 Lift upper cheek using tongue depressor, staying away from teeth.
- 4 Place lorazepam drops or tablets as far back in cheek as possible.
- 5 Rub exterior of cheek to aid absorption through cheek/gum tissue.
- 6 Do NOT expect student to swallow!

Nasal Midazolam:

Remove and discard green vial adapter cap.

Pierce medication vial with the syringe vial adapter.



Aspirate proper volume of medication for student from medication vial (allow extra 0.1 ml for dead space in device.)

Remove (twist off) vial adapter and apply spray adapter.

Place student briefly on back (if you can do so safely). Administer half of medication in each nostril. Too much medication in one nostril will drip back out.

A bloody nose or excessive nasal mucus secretions will reduce absorption. Consider suctioning blocked nostrils before administration if possible.

Once medication has been absorbed, turn student back on their side.

AFTER ANY RESCUE MEDICATION:

Note time and dose given. Keep student on side and observe:

- Color
- Breathing
- Seizure/resolution/progression



School Nurse Support for Students with Epilepsy

STAY CALM—TIME SEIZURE—ASSURE SAFETY NOTHING IN THE MOUTH!

For Partial (wandering) and Absence (staring) Seizures:

- Stay Calm and consult Seizure Action Plan
- Time and record seizure
- Don't grab or yell at student
- Stand between student and danger
- Stay with student until normal function/awareness returns
- Reorient student
- Repeat information student missed

TONIC CLONIC/CONVULSIVE— SEE REVERSE

CALL 911 WHEN:

- Seizure lasts 5 minutes or more (not including recovery time)
- 3 or more seizures in 1 hour without fully returning to consciousness
- Seizure is unusual for that student
- Fluids have been aspirated
- Student is injured, pregnant or has diabetes

Seizure Recovery:

- Allow students to recover according to their needs
- Some students will need to sleep it off
- Some students may experience terrible post-ictal headaches

AFTER THE STUDENT HAS RECOVERED, COMPLETE THE SEIZURE OBSERVATION FORM.

Appendix K: Educational Presentation for School Bus Drivers (Project Access –Nebraska Telehealth for Children with Epilepsy)

Epilepsy & the School Bus Driver




Thanks to Epilepsy Foundation of Georgia for the design and use of some of their slides.

EPILEPSY FOUNDATION®
NORTH/CENTRAL/EAST/CENTRAL/FLORIDA/GEORGIA
"No matter how hard you try, you can't prevent it."

EPILEPSY FOUNDATION®
GEORGIA
"No matter how hard you try, you can't prevent it."

Presentation funded by Health Resources and Services Administration's Maternal and Child Health Bureau, "Project Access – Nebraska-Telehealth for Children with Epilepsy" Grant # H98MC20270



Dispelling Common Myths



- ☐ Most seizures are NOT medical emergencies
- ☐ Most seizures in epilepsy are NOT convulsive.
- ☐ Children can outgrow their epilepsy.
- ☐ Medication does not stop all seizures.
- ☐ People with epilepsy are not necessarily developmentally delayed nor mentally ill.
- ☐ The tongue **cannot** be swallowed during a seizure
- ☐ Never put anything **in the mouth** of a person having a seizure
- ☐ Epilepsy is not contagious
- ☐ Epilepsy can begin at any age from fetus up to 99+.


2

Epilepsy is....




- ☐ A condition of **recurrent** and **unprovoked** seizures
- ☐ "Seizure Disorder" = Epilepsy + PNES
- ☐ Greek word **επιληψία** : seized by forces from without

What is a Seizure?



- ☐ Excessive/disorderly discharge of nerve tissue
- ☐ Imbalance between **excitation** and **inhibition** of nerve cell activity
- ☐ Seizures can be many things – depending on
 - **where in the brain** and
 - **how much of the brain is affected**




Epilepsy is common!

“The statistics are stark and sobering— and for the uninitiated (which is to say most of us), startling. **Epilepsy in America is as common as breast cancer**, and takes as many lives.”

- **1 in 26** will develop epilepsy at some time during their life!
- Inst. of Medicine, March 2012: <http://www.iom.edu/Reports/2012/Epilepsy-Across-the-Spectrum.aspx>


[Jon Meacham in Newsweek, April 10, 2009]

5



Incidence Rate for Seizures at School


- 1:50 people under the age of 18 (potentially 1 student in each standard size bus)
- **1:3 students with a developmental disability**
 - (highly likely in special education bus fleet)



Bus Driver Support for Children with Epilepsy


- **Be a good driver! Pull over safely.**
- **Stay calm** during a seizure!
- **Be supportive** & encourage positive peer interaction!
- **Be familiar** with child's Seizure Action Plan and seizure patterns
- **Know** the child's medications & side effects


7



Special Issues to Consider

- Is student in a wheelchair / mobile?
- Coordination with dispatch: When? & How?
- Keeping other students calm & safe
- “Rescue Medication”-Does student use one?
- Does student have an IEP or IHP?





Special Challenges

- Communicating with parents
 - Language barrier
 - Parents unwilling/unable to share information
 - Parents in denial
- Medically fragile students
- Finding a responsible adult at drop off.
- Bullying by other students




Eileen P.G. Vining, MD Johns Hopkins University:

“**Anything** your brain can do normally, it can do abnormally as a seizure.”



10




What can seizures look like:

• Fainting	• Sleep disorders
• Migraines	• Tourette's
• Behavior disorders	• Panic Attacks
– ADHD	• Movement disorders
– Oppositional Defiant Disorder	

* **Psychogenic Non-Epileptic Attack [PNEA]**

11



Signs of Seizures in Children


- Short **attention blackouts**
- Sudden **falls** for no reason / Unexplained **clumsiness**
- Brief periods of **unresponsiveness**
- Unusual **sleepiness & grouchiness** when awakened from sleep
- Frequent complaints that they see, smell, taste or hear “funny” or “strange” things (**Strange sensory experiences**)
- Confusion/sleepiness following sudden **stomach pain**
- Repeated **unnatural movements** that look strange

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Previous Terminology

- **Grand mal:** convulsive seizure
 - Generalized Tonic-Clonic Seizures
- **Petit mal:** any non-convulsive seizure
 - Absence
 - Complex Partial



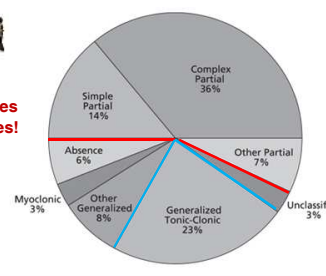
Current Terminology Types of Seizures

Partial (or Focal) Seizures	Generalized Seizures
<ul style="list-style-type: none"> • Simple Partial • Complex Partial <ul style="list-style-type: none"> – Awareness impaired/lost • Partial Seizures can secondarily generalize 	<ul style="list-style-type: none"> • Absence <ul style="list-style-type: none"> – Typical – Atypical • Myoclonic • Tonic-Clonic • Atonic




Incidence of Seizure Types

Over ½ of all epilepsy seizures are partial seizures!

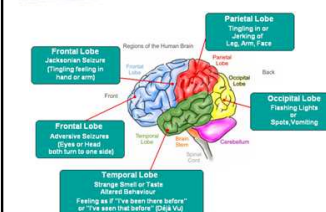


Less than ¼ are convulsive!


Based on Information from *Epilepsy—A Comprehensive Textbook*, J. Engel Jr & T.A. Pedley, editors, Lippincott-Raven, 1998



Partial (Focal) Seizures



Motor
Sensory/Perceptual
Autonomic
Psychic




Seizure? or Behavior?

SEIZURES ARE:	BEHAVIORS ARE:
<ul style="list-style-type: none">• Stereotypical<ul style="list-style-type: none">– Same behaviors– In the same sequence• Paroxysmal<ul style="list-style-type: none">– Sudden– unexpected• Unchanged by behavior modification	<ul style="list-style-type: none">• Variable, situation dependent• A response to specific situation or stimuli• Altered by behavior modification techniques


LOOK FOR A PATTERN!

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Complex Partial (Focal) Seizures

- Blank staring
- Unaware of surroundings - but able to move
- Unresponsive or inappropriately responsive
- Repetitive movements of mouth and/or hands
- Confused speech / repetitive phrases
- Usually lasts 2-4 minutes



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First Aid: Complex Partial

1. **Pull over. Stop bus** as safely as possible.
2. **Protect** from hazards. Contact Dispatch.
3. **Time** the seizure.
4. **Speak softly & calmly.**
5. **Don't grab** or hold. Allow student to move as is safe.
6. **Follow emergency protocol** if seizure lasts >5 minutes or is unusual for that student.
7. Make sure student is dropped off with a **responsible adult**



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Absence Seizures (Petit mal)

- **Most common** seizure type in primary & elementary school students
- **Blank staring**, possible eye blinking/rolling
- **Unresponsive** to outside stimulus
- **Automatic behaviors** (lip smacking, picking at clothes)
- Last a matter of **seconds**

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First Aid: Simple Partial & Absence

- Stay calm
- Protect from harm
- Reassure all students
- Time & Observe the seizure
- Document & Report



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Tonic Clonic Seizures (grand mal)

- Shaking / convulsive activity
- Teeth grinding
- Shallow breathing
- Loss of consciousness / unaware of surroundings
- Fluids from mouth
- Usually lasts 2-4 minutes (occasionally longer)



First Aid: Tonic-Clonic

1. Pull over & stop. Contact Dispatch.
2. Cushion **head**. **Protect** from injury.
3. Turn on side and keep **airway** clear
4. **NOTHING** in the mouth
5. **Time** and Observe seizure.
6. Don't hold down.
7. Follow seizure action plan, if one exists.
8. Once seizure ends, leave student with responsible adult.



Turn on side. Remove harmful items



Cushion & protect head



DON'T put anything in the mouth



Time the seizure




Check for a medical I.D. card




DON'T restrain or hold down

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Seizure in a Wheelchair

- Do not remove from chair unless absolutely necessary
- Secure wheelchair
- Fasten seatbelt loosely to prevent falling from chair.
- **Support & Protect head**
- **Keep airway open** and allow secretions to flow from mouth
- **Pad wheelchair** to prevent further injury
- Follow student's seizure first aid plan.




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Status Epilepticus: A Neurological Emergency

- **30 minutes or more** of seizure activity
- **3 or more** seizures within 1 hour
- **Continuous** / seizure after seizure without stopping
- **Life threatening**—Seek immediate emergency care


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What makes a seizure an **EMERGENCY**?

- **First time seizure**
- Convulsive seizure lasting **>5 minutes**
- **Repeated seizures** without regaining awareness
- More seizures than usual, or change in type
- Student is injured, has **diabetes** or is **pregnant**
- Fluid has been inhaled into lungs
- Distance to medical help is unknown or excessive


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What Can Trigger A Seizure?

- Missed or late medication (#1 reason)
- Stress/anxiety
- Lack of sleep / fatigue
- Poor diet / Missed meals
- Constipation / Full bladder
- Drug interactions (antibiotics!)
- Menstruation
- Flashing lights
- Hyperventilation
- Overheating/overexertion

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Seizure Observation

- Detailed seizure reporting helps the treating physician.
- Identifies:
 - **seizure triggers**
 - **patterns**
 - **precautions**

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Observation




Seizure Observation Record

Student Name:			
Date & Time:			
Seizure Length:			
Pre-ictal Observation (Briefly list behaviors, triggering events, activities):			
Convulsion (seizure) observed:			
Injuries (briefly describe):			
Motor/Trunk/Body Movements	Rigid/clenching		
	Clonus		
	Fall down		
	Rocking		
Extremity Movements	Spontaneous arm/leg		
	Stiff arm/leg		
	Stiff arm/leg		
	Stiff arm/leg		
Other	Bluish		

Seizure Observation Form available from: www.epilepsyfoundation.org


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Treatment of Epilepsy

- 
- **Lifestyle modifications**
 - **Medication**
 - **Surgery**
 - Brain surgery
 - VNS = Vagus Nerve Stimulator
 - **Diet Therapies**


30

Lifestyle Changes Can Help


- 
- **Dietary:**
 - Caffeine – Avoid it!
 - Insulin spikes – Avoid them! (eat a low glycemic diet)
 - No alcohol
 - Regular **Schedule & Sleep** (Get enough of it!)
 - **Stress**
 - Avoid it
 - Use relaxation techniques
 - Avoid Seizure **Triggers**
 - Flashing lights in only 1 to 3% of people with epilepsy

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Medication: The Main Therapy

- 
- **Monotherapy** control in 50-60%
 - **Polytherapy:** additional 10-20% controlled
 - **Treatment resistant:** 20-30%
 - **Side effects!** All epilepsy drugs have potential side effects, some serious.


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Side Effects Bus Drivers May See

- **Sleep:** Difficulty falling asleep / staying asleep / Sleeping all the time
- **Appetite:** ↑ OR ↓
- **Behavior:** Hyperactivity and/or Aggression
- **Fatigue, Dizziness, Blurred Vision**
- **Slowed thinking:**
 - Forgetfulness
 - Short term memory problems
 - Word recall problems

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Dangerous Side Effects

- **Liver** inflammation / failure
- **Blood**
 - Aplastic Anemia
 - Seriously low white blood cell counts
 - Seriously low platelet counts
- **RASH!** – Stevens-Johnson Syndrome
 - Any epilepsy patient with a rash should consult their treating physician immediately

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RASH: Refer to physician

Mild Stevens-Johnson Syndrome



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More AED Side Effects

- **Bone loss** – osteoporosis
- **Dental** – gum overgrowth & swelling
- **Leg cramps**
- **Skin** – Acne, rash, brown spots
- **Hair** – overgrowth OR breakage/loss
- Some **antibiotics** decrease effectiveness of the epilepsy medication

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VNS: Vagus Nerve Stimulator



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First Aid: VNS Magnet



- ✓ One quick swipe of magnet over device (usually left chest just below collarbone).
- ✓ Wait 1 minute and swipe again if needed.

<http://us.cyberonics.com/en/vns-therapy-for-epilepsy/patients-and-families>

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VNS: Difficulties

- Side Effects
 - Coughing
 - Hoarseness or voice changes
 - Shortness of breath
 - Throat pain
 - Sleep apnea
- Must be programmed and reprogrammed
- Battery runs out & must be changed surgically

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Rescue Medications

Rectal diazepam gel



Bucal lorazepam




Midazolam Nasal Spray






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Seizure Preparedness at School

- Forms available from Epilepsy Foundation
 - ✓ Seizure Action Plan
 - ✓ Parent Questionnaire (Child has Epilepsy)
 - ✓ Seizure Observation Record
- www.epilepsyfoundation.org/livingwithepilepsy/educators/socialissues/schoolnurseprogram/index.cfm


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Seizure Action Plan


- Individualized
 - seizure/health information
 - seizure first aid & emergency response
- Prepared by: School Nurse & Parents
- Approved by: Treating physician
- Distributed to relevant school personnel
 - At diagnosis
 - At beginning of school year,
 - Change in health status occurs

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Epilepsy Education for Students

- Elementary: “Thinking About Epilepsy”
- Middle/High School: “Take Charge of the Facts”




43



Seizure First Aid: Review

- Basic first aid depends on type of seizure:
 - No change in consciousness (**Simple Partial Seizure**)
 - Altered Awareness (**Complex Partial Seizure** and **Absence**)
 - Loss of Consciousness / Convulsions (**Generalized Tonic-Clonic**)

44



Seizure First Aid: Review

- Stay calm!
- Most seizures are **not** medical emergencies
- Always **time** a seizure!
- Nothing in the mouth
- Don't hold down

45



Epilepsy Foundation Video

Share this video!

<http://www.epilepsyfoundation.org/livingwith/epilepsy/educators/index.cfm>

(Scroll to bottom of page.)

46



Who has epilepsy?

Supreme Court Justices And Doctors





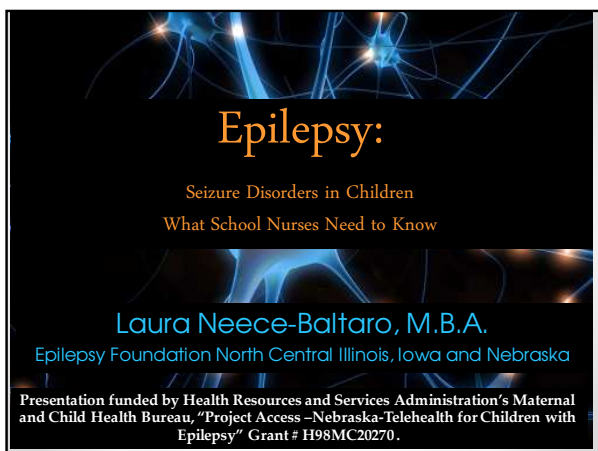
Resources

- **Epilepsy Foundation:** (800) 332-1000, Email: ContactUs@efa.org, www.epilepsyfoundation.org
- Your local affiliate: EFNCIL, (800) 221-2689 www.epilepsyheartland.org
- www.epilepsyclassroom.com
- www.epilepsy.com



Presentation funded by: Health Resources and Services Administration's Maternal and Child Health Bureau, "Project Access -Nebraska-Telehealth for Children with Epilepsy" Grant # H98MC20270

Appendix L: Educational Presentation-Overview of Epilepsy: Managing Seizures in Schools



When is it epilepsy?

- ▣ **Recurrent** and **unprovoked** seizures
- ▣ 2 or more seizures
 - ▣ without a clear cause (e.g. insulin, alcohol withdrawal or poisoning)
- ▣ **"Seizure Disorder" = Epilepsy**
 - ▣ Also includes Psychogenic Non-Epileptic Attacks (PNEA)

What is a Seizure?

- ▣ Excessive/disorderly neuron discharge
- ▣ Imbalance in **excitation** and **inhibition** of neurons
- ▣ Seizures are many things – depending on
 - **where** in the brain and
 - **how much** of the brain is affected

Eileen P.G. Vining, MD Johns Hopkins University:



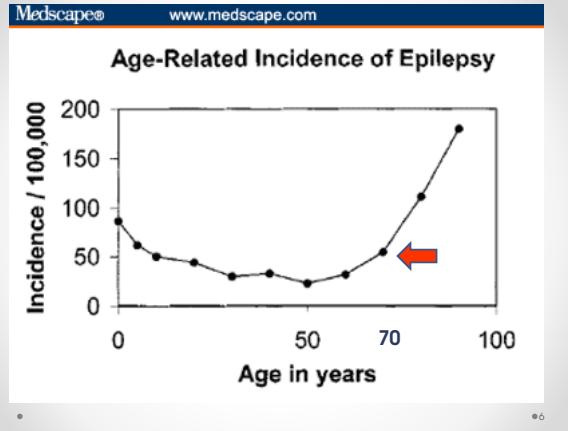
"Anything" your brain can do normally, it can do abnormally as a seizure."

Epilepsy is common!

"The statistics are stark and sobering—and for the uninitiated (which is to say most of us), startling. **Epilepsy in America is as common as breast cancer**, and takes as many lives."

(Jon Meacham in Newsweek, April 10, 2009)

- **1 in 26** will develop epilepsy at some time during their life!
- Institute of Medicine, March 2012: <http://www.iom.edu/Reports/2012/Epilepsy-Across-the-Spectrum.aspx>



Causes of Epilepsy

Anything that alters and changes the brain tissue or the neurons.

- Genetics
- **Trauma / head injury**
- Stroke
- Brain Lesions & Malformations
- Infection / Inflammation (of central nervous system)
- Neurodegenerative Disease
 - Alzheimer's – 5% develop epilepsy
- **Systemic Diseases increase the risk**
 - Hypertension, diabetes, celiac disease, lupus

Seizure Triggers

- Missed or late medication (#1 reason)
- Stress/anxiety/fear
- Lack of sleep / fatigue
- Drug interactions (antibiotics!)
- Overheating / overexertion
- Poor diet / missed meals
- Flashing lights (or other sensory stimuli)
- Hyperventilation
- Menses / hormonal changes
- Alcohol / drug use / poisoning

Classification of Seizures

Partial (or Focal) Seizures

- **Simple Partial**
 - Awareness not impaired
- **Complex Partial**
 - Awareness impaired/lost
- **Partial Seizures secondarily generalizing**

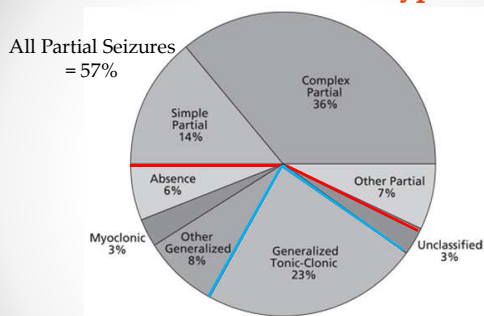
Generalized Seizures

- **Absence**
 - Typical
 - Atypical
- **Myoclonic**
- **Clonic**
- **Tonic**
- **Tonic-Clonic**
- **Atonic**

Status Epilepticus: A Neurological Emergency

- A prolonged seizure state lasting **30 minutes or more**
- 3 or more seizures occurring within 1 hour
- Patient seizes continuously or has seizure after seizure without stopping
- Life threatening—Seek immediate emergency care

Incidence of Seizure Types



Based on Information from Epilepsy—A Comprehensive Textbook, J. Engel Jr & T.A. Pedley, editors, Lippincott-Raven, 1998

Partial Seizures

also known as
Focal Seizures

- Motor
- Sensory/Perceptual
- Autonomic
- Psychic

Partial MOTOR Seizures

- **Muscles**
 - Specific muscles
 - Groups of muscles
- **Abnormal Movements**
 - Stiffening
 - Rhythmic Contracting
 - Complete loss of tone

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Partial SENSORY Seizures

- **Auditory**
 - hallucinations: buzzing, ringing, music, speech
- **Visual**
 - Blurring, blindness, hallucinations
- **Touch**
 - Tingling, numbness, burning sensations
 - Sensation of a light touch to the skin
- **Olfactory**
 - Intense unpleasant smells
- **Taste**

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Partial AUTONOMIC Seizures

- **Heart:** Rate / Blood pressure
- **Breathing:** Rate
- **Skin:** Temperature / Sweating / Flushing
 - Piloerection = Goose bumps
- **Eyes:** Pupil dilation
- **Digestive:** movement / noises / vomiting

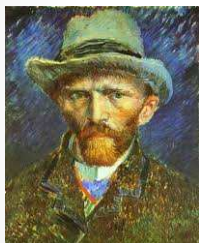
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Partial PSYCHIC Seizures

- | | |
|---|--|
| <ul style="list-style-type: none"> • Emotions: <ul style="list-style-type: none"> ◦ Fear ◦ Dread / Foreboding ◦ Anger ◦ Laughter (Gelastictic seizures) ◦ Crying (Dacrystic seizures) | <ul style="list-style-type: none"> • Memory: <ul style="list-style-type: none"> ◦ Dejà vu ◦ Jamais vu ◦ Loss of (dysmnesic) • Language <ul style="list-style-type: none"> ◦ Word finding ◦ Total loss |
|---|--|

• 16

Partial Seizures: Van Gogh & Lewis Carroll



Visual, spatial &
psychic seizures



The Illness of Vincent van Gogh
Dietrich Blumer, M.D.

• Am J Psychiatry 2002;159:519-526. 10.1176/appi.ajp.159.4.519

• 17

Diagnostic Tools for Epilepsy

- Observation
- EEG
- MRI
- MEG



• 18

Observation

Seizure Observation Record	
Student Name: _____	
Date & Time: _____	
Seizure Length: _____	
Pre-Seizure Observation (Briefly list behaviors, triggering events, activities): _____	
Consciousness (postictal state): _____	
Injuries (briefly describe): _____	
Motor/Tonicic Movements	Right clenching
	Left
	Right down
	Right
	Right arm jerking
Clonus/Myoclonic Movements	Right arm jerking
	Left arm jerking
	Right jerking
	Left jerking
	Random Movement
Other	Blank

Seizure Observation Form
available from:
www.epilepsyfoundation.org

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Seizure Observation

- Detailed seizure reporting helps the treating physician.
- Helps to identify
 - **seizure triggers**
 - **patterns**
 - **precautions**

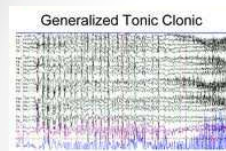
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Observation: Keeping an Epilepsy Diary

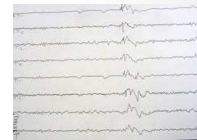
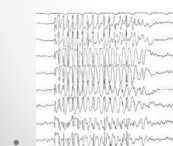
- <https://www.webease.org/Overview.aspx>
- <https://seizuretracker.com/>
- <http://www.epilepsy.com/seizurediary>
- <http://seizurediary.org/>

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EEG=Electroencephalography



Absence Seizure ↓



Temporal Lobe Epilepsy ↑



What the EEG is and is NOT

• It is:

- A **snapshot** of brain activity
- **Surface electrodes** trying to measure deep brain electrical activity

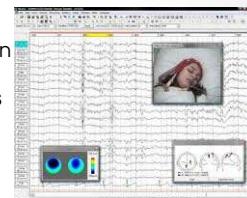
• It is NOT a definitive diagnosis

- Normal EEG only means no abnormal activity during the EEG
- Abnormal activity doesn't always mean epilepsy

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Overcoming EEG's drawbacks

- **24-hour video EEG** monitoring matches brain wave activity to behaviors / motor events over time



- **Intracranial EEG grids** detect deeper seizure activity -- **INVASIVE**

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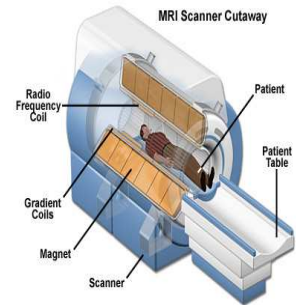
Ambulatory EEG



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MRI

- A normal MRI does not rule out epilepsy
- Normal MRI a good sign:
 - Better response to medication
 - Monotherapy
 - Less side effects!
 - Children more likely to outgrow the epilepsy.



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Why an MRI?

- To rule out treatable conditions:
 - tumors,
 - venous malformations,
 - aneurysms, etc.
- To determine the location and extent of any abnormal or scarred brain tissue.
 - Should epilepsy surgery be considered?

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MEG

- Measures magnetic fields produced by seizures
- Identifies seizure focus
- Non-invasive
- Surgical decision assist



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Differential diagnoses

- Fainting
- Migraines
- Behavior disorders
 - ADHD
 - Oppositional Defiant Disorder
- Sleep disorders
- Tourette's
- Panic Attacks
- Movement disorders
 - Parkinson's

* Psychogenic Non-Epileptic Attack (PNEA)

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Possible Signs of Seizures

- Short attention blackouts
- Sudden falls for no reason / Unexplained clumsiness
- Brief periods of no response
- Unusual sleepiness and grouchiness when awakened from sleep
- Frequent complaints that things they see, smell, taste or hear are "funny" or "strange"
- Confusion and sleepiness following sudden stomach pain
- Repeated movements that look strange or unnatural
- In infants:
 - Clusters of "jackknife" movements in babies
 - Clusters of grabbing motions with both arms by babies

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Seizure? or Behavior?

SEIZURES ARE:

- **Stereotypical**
 - Same behaviors
 - In the same sequence
- **Paroxysmal**
 - Sudden
 - unexpected
- **Immutable** by behavior modification

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BEHAVIORS ARE:

- **Variable**, situation dependent
- **Responsive** to specific situation or stimuli
- **Mutable** by behavior modification techniques

Comorbidities

- **Intellectual Disability**
 - Approximately 30% will also have epilepsy
- **ADHD**
 - Children with ADHD 2 to 5 times as likely to have epilepsy
- **Autism**
 - 27-65% have EEG abnormalities.
 - Up to 35% may develop some form of epilepsy
- **Cerebral Palsy**
 - 20-30 % will also have epilepsy

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Psychiatric Comorbidities

- In Generalized Epilepsy
 - Impulse control
 - Short attention span
 - Easily frustrated
- In Partial Epilepsy
(Most common in frontal lobe or temporal lobe foci)
 - Depressed
 - Anxious
 - Psychotic
 - In CHILDREN: ADHD, ODD, aggression, impulsivity

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Prognosis: Pediatric Epilepsy

From www.epilepsy.com:

- **Most children outgrow their epilepsy** – but hard to predict which ones.
- **Best chance of outgrowing:**
 - Development, EEG, MRI are all normal
 - Medications control seizures completely.
- **Certain types usually outgrown:**
 - Reflex epilepsies
 - Benign Rolandic Epilepsy (ends @ age 15-16)

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Treatment of Epilepsy

- **Lifestyle changes**
- **Medication – AED's** (Anti Epilepsy Drugs)
- **Surgery**
 - VNS = Vagus Nerve Stimulator
- **Diet Therapies**

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Lifestyle changes

- **Dietary:**
 - Avoid caffeine
 - Avoid insulin spikes (eat a low glycemic diet)
 - No alcohol
- **Regular Schedule**
- **Sleep** – Get enough of it!
- **Stress**
 - Avoid it!
 - Use relaxation techniques
- **Avoid Seizure Triggers**
 - Flashing lights in only 1 to 3% of people with epilepsy

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AED Side Effects

- Cognitive slowing
- Fatigue, Dizziness, Blurred Vision,
- **Sleep** (falling asleep, staying asleep, always sleepy)
- **Appetite:** ↑ OR ↓
- **Behavior:** Hyperactivity & Aggression
- **Leg cramps** – lack of potassium
- **Appearance:**
 - **Skin** – Acne, rash, brown spots
 - **Hair** – overgrowth OR breakage/loss
 - **Dental** – gum hyperplasia
- **Osteoporosis**
- Other medication interactions: **antibiotics & birth control.**

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Dangerous Side Effects

- **Liver** inflammation / failure
- **Blood**
 - Aplastic Anemia
 - Seriously low white blood cell counts
 - Seriously low platelet counts
- **RASH!** – Stevens-Johnson Syndrome
 - Any epilepsy patient with a rash should consult their neurologist immediately
- **Birth Defects** – Teratogenicity!

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Mild Stevens-Johnson Rash



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Epilepsy Standards of Care

National Association of Epilepsy Centers
www.naec-epilepsy.org/spec_care/guidelines.htm

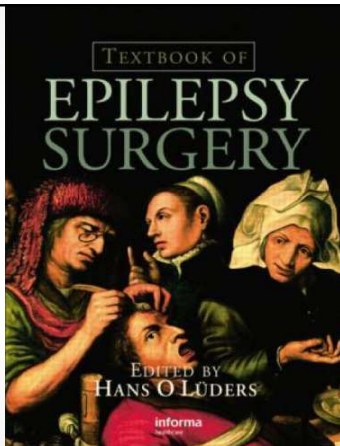
Delayed or denied referral may be detrimental to the patient's health, safety and quality of life.

Uncontrolled seizures after **three months of care by a primary care provider** (family physician, pediatrician), should be referred to a neurologist, or an epilepsy center if locally available.

After **12 months of care from a neurology specialist**, if the seizures are still not controlled, patient should be referred to a specialized epilepsy center with an epileptologist.

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Good Surgical Candidates

- Single seizure focus
 - Temporal lobe focus
 - **Failed trials of 2 or 3 AEDs**
- And / Or
- Seizures are life threatening

Types of Surgery

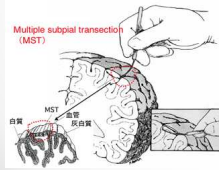
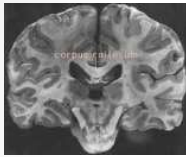
- Resection
- Disconnection
- Hemispherectomy

Resection



- **Most common epilepsy surgery**
 - Anterior temporal lobectomy
- Removal of the area causing the seizures

Disconnection



- **Corpus callosotomy**
- **Multiple subpial transections**
 - Relief, not a cure
 - Used for areas of the brain that cannot be removed

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Hemispherectomy



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Surgical Outcomes

- **Outcome / Prognosis**
 - Most patients get some relief of their seizures
 - Less frequent
 - Less severe
- **Factors predicting success**
 - Seizures coming from one localized focus
 - Normal MRI
 - Normal EEG between seizures
 - Surgery at major epilepsy surgery center


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Dietary Solutions


- **Ketogenic Diet**
- **Modified Atkins**
- **Low Glycemic Index Diet**

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The Charlie Foundation Presents
AN INTRODUCTION TO THE
KETOGENIC DIET
A TREATMENT FOR
PEDIATRIC EPILEPSY



One Cheerio is enough carbs to ruin the diet.



Carbohydrate: 2%
Protein: 8%
Fat: 90%

www.charliefoundation.org

ALSO
A KIDS INTRODUCTION TO
THE KETOGENIC DIET

Ketogenic Diet: Difficulties

- **Mostly FAT:** 90% calories from fat
 - unpalatable and boring
- **Restricts calories:** 75-90% caloric requirement!
- **Restricts fluids** – don't wash away ketones!
- **Weigh & measure carefully** – ALL intake
 - Well-educated, committed parents
 - A very precise (expensive) scale
- **Frequent recalculation** during growth spurts

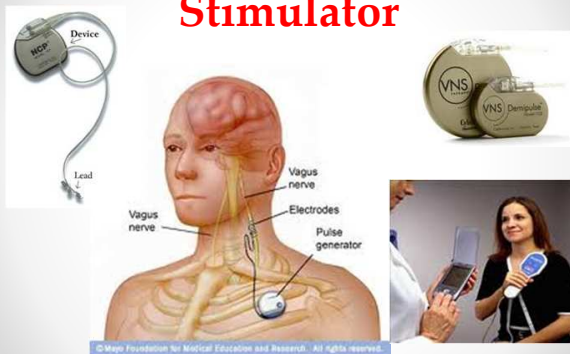
Ketogenic Diet: Difficulties (cont.)

- Professional supervision required!
- Carbs kept under lock & key
- Unexpected Carbohydrates – BEWARE!
 - Certain **SUNSCREENS**
 - Some **sugarless gums**
 - Certain **TOOTHPASTES**

Modified Atkins and Low Glycemic Diets

- Goal: Stable sugar and insulin levels
- Used with medication, not instead of
- Easier than Ketogenic Diet

VNS: Vagus Nerve Stimulator



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VNS: Pros & Cons

- | | |
|---|---|
| <ul style="list-style-type: none"> • Less seizures • Efficacy can increase over time • Often alleviates depression • Dosages of medications can sometimes be reduced (→less side effects) | <ul style="list-style-type: none"> • Not a cure • Side Effects: <ul style="list-style-type: none"> ◦ Coughing/Hoarseness/voice changes ◦ Shortness of breath ◦ Throat pain ◦ Sleep apnea • Must be programmed and reprogrammed • Battery must be changed surgically • Leads on vagus nerve difficult to remove |
|---|---|

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Seizure 1st Aid: VNS Magnet



- 1 sec. swipe over device (usually left chest just below collarbone).
- Multiple swipes OK (wait 1-2 minutes between)
- Do NOT hold it continuously over device (turns it off).



<http://us.cyberonics.com/en/vns-therapy-for-epilepsy/patients-and-families>

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Seizure First Aid

- Most seizures are **not** medical emergencies
- Basic first aid depends on type:
 - **Conscious & Aware**
 - (Simple Partial Seizure)
 - **Awareness altered or absent**
 - (Complex Partial Seizure)
 - (Absence Seizure)
 - **Loss of Consciousness**
 - (Generalized Tonic-Clonic)

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First Aid: Simple Partial

- Stay calm
- Reassure student
- Time the seizure
- Explain to others, if necessary
- Protect student's privacy

© 61

First Aid: Complex Partial

1. Time the seizure
2. **Speak softly & calmly**
3. **Don't grab or hold**
4. **Protect from hazards**
5. Allow for wandering in contained area
6. Be prepared in case the seizure generalizes (becomes convulsive)
7. Emergency protocol if seizure lasts >5 minutes or beyond what is usual for that student.



© 62

First Aid: Tonic-Clonic

1. Cushion **head**.
2. Turn on side and keep **airway** clear
3. **Protect** from harm.
4. **NOTHING** in the mouth
5. Observe & **time** events
6. Don't hold down.
7. Follow seizure action plan, if one exists.



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Seizure in a Wheel-chair

First Aid for Seizures in a Wheel Chair

Do:

- Stay with the person
- Time the seizure
- Apply the wheelchair brakes
- Leave person in chair with seat belt on
- Recline backrest only—do NOT tilt chair
- Lean person slightly to one side to aid drainage of any fluid/food in mouth
- Support head and protect airway
- After seizure has stopped, carefully remove from chair and place in recovery position—lying on side, if possible
- Observe and reassure until completely recovered

Do Not:

- Put anything in the mouth
- Restrain the person
- Tilt or tip the wheelchair

CALL 911 IF:

- Injury has occurred
- There is liquid/food/vomit in mouth
- Seizure occurs in water
- Another seizure follows
- Shaking or seizure lasts more than 5 minutes
- Breathing is difficult after the seizure

This is not medical advice nor an indication that you are a nurse or doctor. This is a guide to help you understand your responsibilities as a caregiver. If you are in any doubt about what to do, do not hesitate to call 911.

EPILEPSY FOUNDATION

Epilepsy Foundation World Center/US, One and One-half
 609 N. 1st Street, Suite 200, St. Louis, MO 63102-3242
 (800) 451-1173 / info@epilepsy.org

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What makes a seizure an EMERGENCY?

- First time seizure
- Convulsive seizure >5 minutes
- Repeated seizures without regaining awareness
- More/Different seizures than usual
- Diabetes or pregnancy
- Fluids may have been aspirated
- Student is injured
- Parents request emergency evaluation

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Rescue Medications:

Rectal diazepam gel



Buccal lorazepam (Ativan)



Midazolam Nasal Spray



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Nasal Midazolam

- **Suction** nostrils, if not clear (blood, mucus, etc.)
- Prepare proper medication **dosage**
- Apply **spray adapter**
- Place student briefly **on back** (if safe to do so)
- Spray half medication in **each** nostril.
- Once medication has been absorbed, return student to side.



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Buccal Lorazepam

- **Student on side**
- **Wipe** away excess saliva
- **Lift** cheek
 - Use tongue depressor & stay away from teeth
- **Place** drops/pills as far back in cheek as possible
- **Rub** exterior of cheek to aid absorption of medication
- Do not expect the student to swallow



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RECTAL DIAZEPAM

Dosage locked in
by **pharmacist**

Caregiver
confirms correct
dosage in
window on barrel.



<http://www.diastat.com/hcps/about/dosing-administration.aspx>
<http://www.epilepsyfoundation.org/resources/epilepsy/loader.cfm?csModule=security/getfile&pageid=21461>

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Preparing

- Lay student **on their side** in safe place.
- Check **correct dosage** in window on barrel.
- **Remove cap** from plunger tip.
- Be sure the **plastic sealing pin** is inside the cap and has been removed from barrel.
- Open packet of **lubricating jelly** and stick tip of syringe in – lubricating well.
- With student facing you, **bend upper leg forward** toward you to expose rectum.

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Administering

- Gently & slowly insert tip into rectum.
- Gently & slowly (COUNT 1-2-3) **push plunger** until it stops.
- **Leave syringe in** rectum while **slowly counting to 3** again.
- Remove syringe from rectum while **holding buttocks together** for another **slow count of 3**
- Note time given, keep student on side and continue to observe.

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Diastat Administration 3 slow counts of 3!



http://www.epilepsyinfo.org/Resources/Diastat_Administration.pdf

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Rectal diazepam: Eventualities

- **Sleepiness** – student may need to sleep it off.
- **Diarrhea** – hold buttocks closed to avoid diarrhea. Student should be on side, facing you.
- **Respiratory inhibition** – only 1% (or less) of patients.

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School Nurse is Key!

- **Assess** student needs / gather information
 - Parent questionnaire
 - From teachers & school staff
 - Seizure triggers
 - Impact on learning & behavior
- **Customize** a Seizure Action Plan
- **Train** staff & tailor interventions
- **Solicit** compassion and acceptance from other students!

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Forms from Epilepsy Foundation

- Seizure Action Plan
- Seizure Observation Record
- Parent Questionnaire

All available from:
EpilepsyFoundation.org

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The Seizure Action Plan

- **Individualized**
 - seizure/health information
 - seizure first aid & emergency response
- **Prepared by:** School Nurse & Parents
- **Approved by:** Treating physician
- **Distributed to** relevant school personnel
 - At diagnosis
 - At beginning of school year,
 - Change in health status occurs

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Seizure Observation Record

- **Helps to identify**
 - seizure triggers
 - patterns
 - precautions.
- **Helps the treating physician**

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Suggestions for School Nurses

- **LOG** to communicate with parents/guardians
- **LIAISON** – between parents and teachers (re changes in status or health)
- **COACH** teachers to regularly note physical, emotional or cognitive changes
- **CREATE** “substitute teacher” folder with:
 - Seizure Action Plan
 - Seizure first aid and other relevant information
- **EDUCATE** classmates and school staff

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Training School Staff

- **ON LINE: Seizure Training for School Personnel**
 - <http://www.epilepsyfoundation.org/livingwiththeepilepsy/educators/socialissues/helpingchildrenunderstand/trainingforteachersandschoolpersonnel/seizuretrainingforschoolpersonnel.cfm>
 - Video
 - Power Point
 - Learning Assessment
- **KIT: Seizure Training for School Personnel**
 - <http://shop.epilepsyfoundation.org/store/p/804-Seizure-Training-for-School-Personnel-Kit.aspx>
 - DVD
 - PowerPoint
 - Handouts
 - Learning Assessment

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Epilepsy Education for Students

- **Elementary:** Thinking About Epilepsy
- **Middle School:** Take Charge of the Storm
- **High School:** Take Charge of the Facts



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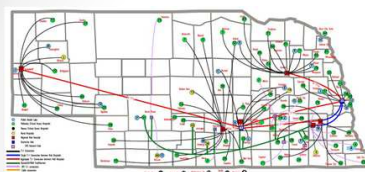
Additional Topics in Epilepsy (if time allows)

- Telehealth for epilepsy
- Hormones and epilepsy
- SUDEP
- Genetics
- Seizure Assistance Dogs
- Who has/had epilepsy

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Telehealth Epilepsy Clinics



Appointments:
308-865-7742



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Hormones & Epilepsy

- Seizures cause both acute and chronic alterations in hormonal secretions. (Epilepsy.com)
- Catamenial Epilepsy – seizures align with menstrual cycle
- Estrogen lowers seizure threshold
- Progesterone raises seizure threshold
- Depakote & Polycystic Ovarian Syndrome: >60% ♀ taking valproate - PCOS (even higher in ♀ < 20 yrs).

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SUDEP

- Epilepsy patients have shorter lifespan
- Mortality rate is 2 – 3 times the background population
- Risk is higher for:
 - Tonic Clonic seizures
 - Nocturnal Seizures
 - Not taking medications as prescribed
 - On 2 or more AEDs
 - Onset at young age
 - Long standing chronic epilepsy

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Genetics & Epilepsy

- To participate in genetic studies:
<http://www.cumc.columbia.edu/dept/epilepsy/>
- Ion channel gene mutations
- Cystatin B protein gene mutation
- Temporal Lobe Epilepsies
- Genetic resistance to AEDs

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Seizure Assistance Dogs

- **Alert vs. Assist** (not all can sense seizures)
- Other ways they can help:
 - Retrieve a phone
 - Push their person into a safe position
 - Pull away dangerous objects
 - Block their person from wandering into danger
 - Summon help in a controlled environment

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Seizure Assistance Dogs Improve Quality of Life

- **Improve the quality of life of a person with epilepsy by:**
 - Staying with their person during a seizure
 - Instilling confidence
 - Providing companionship and
 - Contributing to overall emotional well-being

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Seizure Assistance Dogs Web Sites

- epilepsyfoundation.org/livingwithepilepsy/healthandwellness/Seizure-Dogs.cfm
- In Nebraska: domesti-pups.com
- ucb.com/patients/programmes/canine-assistants
- www.k94life.org (*Canine Partners for Life*)
- www.canineassistants.org
- chelseahutchisonfoundation.org (*Funding help*)

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Alert or Assistance Dogs

- Alert Dogs notify of an on-coming seizure (difficult to train)
- Assistance Dogs can:
 - Retrieve a phone (prior or post seizure)
 - Push their person into a safe position
 - Pull away dangerous objects
 - Block individuals with partial or absence seizures from wandering into danger
 - Summon help in a controlled environment

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Dogs Can Improve Quality of Life

- **Improve the quality of life of a person with epilepsy by:**
 - Staying with their person during a seizure
 - Instilling confidence
 - Providing companionship and
 - Contributing to overall emotional well-being

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Who has epilepsy?

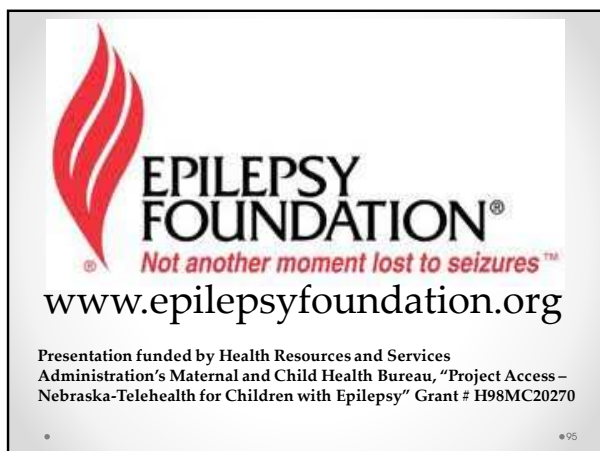
Supreme Court Justices, Doctors and Legislators





Downloadable Epilepsy Information

- www.epilepsyfoundation.org
- www.epilepsyheartland.org
- www.epilepsy.com
- www.epilepsynebraska.com



For more information

about the organizations featured in this toolkit, please contact:

Michigan Department of Community Health

Linda Fletcher

517.241.5071

FletcherL@michigan.gov

Munroe-Meyer Institute, University of Nebraska Medical Center

Linda Cook, PhD or William Warzak, PhD

402.559.5007 wwarzak@unmc.edu

402.559.6408 linda.cook@unmc.edu

Epilepsy Foundation of Western/Central Pennsylvania

Rick Boyle, Special Projects Director

412-322-5880

RBoyle@efwp.org <http://www.efwp.org/>

Cleveland Clinic

Dr. Tatiana Falcone

216.444.7459

Falcont1@ccf.org

Epilepsy Foundation of Florida

Judy Clauser

305.670.4949

jclauser@efof.org <http://www.efof.org/>

New Hampshire Department of Health and Human Services, Special Medical Services

Elizabeth Collins

603.271.8181

ECollins@dhhs.state.nh.us

<http://www.dhhs.nh.gov/dcbcs/bds/sms/index.htm>

National Center

Phyllis George

(301) 459-3700

pgeorge@efa.ofg

www.epilepsyfoundation.org

Epilepsy Foundation of Mississippi

Tress Townsend

(601) 936-5222 (Ext. 301)

tresmsepilepsy@bellsouth.net

<http://epilepsy-ms.org/>