

SEPTEMBER 2008

SNOHOMISH COUNTY CHILD HEALTH NOTES: EPILEPSY

Promoting early identification and partnerships between families, primary health care providers & the community.

Distributed by: Children with Special Health Care Needs Program and the Infant Toddler Early Intervention Program
Contributors: Washington State Department of Health and UW – Center on Human Development & Disability



CARE COORDINATION FOR CHILDREN & YOUTH WITH EPILEPSY

Epilepsy is a chronic neurological condition characterized by two or more seizures.

- The term “epilepsy” can be used interchangeably with “seizure disorder”
- Manifestations of a seizure are varied and may range from staring, lip smacking, eye deviation or generalized tonic-clonic.

Epilepsy is the most common neurological condition in children and impacts 6,100 -15,000 children in Washington State. Functional performance in school, home, daily self-care, and community participation can be significantly impaired. Children and youth with epilepsy are often socially stigmatized and there is a high incidence of depression.

Diagnosis and Evaluation: Role of the Primary Care Provider

- Obtain a detailed description of the suspected seizure activity and events preceding and following the event; if the events occur frequently, a video tape recording of the activity may be helpful. Note: staring spells may be distinguished from day dreaming by the lack of response to physical manipulation during the event.
- Determine if the seizure(s) is due to an acute neurological condition that requires emergency treatment.
- Obtain information from school teachers and/or childcare providers regarding recent changes in behavior, developmental performance, or academic performance
- Perform a full developmental screening test to help identify any possible developmental delays
- Perform a comprehensive physical examination
- Obtain and review results from EEG testing, laboratory evaluations, or other diagnostic measures
- If a referral is needed, gather all of this information together and send it to the consulting Neurologist in advance of the clinic appointment. Providing parents with copies of these reports is also helpful.

Consider using these tools:

Pediatric Neurology Consult and Referral Guidelines

www.seattlechildrens.org/health_care_professionals/pdf/guidelines_neurology.pdf

Developed at Children’s Hospital & Regional Medical Center, offers tips for when it is appropriate to refer a child to a medical specialist and lists other information you can provide to support the consultation.

Guidelines for the Care of Children and Adolescents with a Seizure Disorder

www.ohsu.edu/cdrc/medicalhome/docs/seizure.pdf

R. Nickel & L. Desch (2000). *The Physicians Guide to Caring for Children with Disabilities and Chronic Conditions*

For Consultation with a Pediatric Neurologist:

Community primary care providers within the WWAMI region may consult by telephone with a pediatric neurologist through MEDCON. MEDCON is a toll-free telephone consultation service that connects primary health care providers with School of Medicine Faculty at the University of Washington. (Clinic appointments are not scheduled through MEDCON.)

1-800-326-5300 OR 206-543-5300

Referral Sources: For Child to See a Neurologist

- Children's Hospital & Regional Medical Center, Health Professional Hotline.....1-800-293-2462
- UW Regional Epilepsy Center at Harborview (Seattle).....206-744-3576
- Swedish Epilepsy Center (Seattle).....206-386-3880
- WA Neuroscience Institute (Valley Medical Center, Renton).....425-656-5566

Care Management Tools for Office Practice

Co-management is an optimal strategy for managing care for children with epilepsy and their families. Co-management is coordinated communication between the child & family, primary health care provider, neurologist, medical specialists, and others participating in the child's care. Provider tools and parent materials are available online to support co-management for children with epilepsy.

Care Coordination Tools:

A written care plan may be developed in partnership with the primary care provider and family for the purpose of providing important information to those who care for the child. This may include information about medications, what to do in case of emergency, contact information for care team members, etc... Here are examples of ready-to-use formats.

Family and Physician Management Plan Summary for Children and Adolescents with Seizure Disorder

<http://internet.dscc.uic.edu/forms/medicalhome/manage4.pdf>

Care Plans.....www.cshcn.org/resources/careplans.cfm (English & Spanish)

Parent Materials:

Family Care Coordination Notebook/Organizer.....www.cshcn.org/resources/CareNtbk.cfm (English & Spanish)
(a system for families to organize and manage important health documents)

Seizures/Epilepsy: Answers to Common Questions... www.seattlechildrens.org/child_health_safety/pdf/flyers/PE264.pdf

Safety Tips for Children with Seizures..... www.cshcn.org/Forms/SeizureTips.pdf (English & Spanish)

Water Safety for Children with Epilepsy..... <http://drowning-prevention.org/pdf/CE348.pdf>

Seizures First Aid..... www.cshcn.org/forms/SeizureFirst.pdf (English & Spanish)

New Epilepsy Project in Washington State

The Washington State Health Department (DOH), Children with Special Health Care Needs Program (CSHCN), is leading efforts to improve coordinated care for children and youth with epilepsy through a 3-year federal grant, *Epilepsia en Washington*, from the Maternal and Child Health Bureau. This project targets children and youth with epilepsy living in rural and medically underserved areas of Washington State with an emphasis on Hispanic families.

Planned outcomes include sponsoring education opportunities for physicians and families, development and implementation of epilepsy care management tools, and increasing the use of co-management strategies in caring for children and youth with epilepsy.

To learn more or to inquire about participating in the project, contact:

Yris Lance, Project Coordinator at yris.lance@doh.wa.gov or (360)236-3585

EPILEPSY LINKS:

- **Regional:** Epilepsy Foundation Northwest www.epilepsynw.org
- **National:** Epilepsy Foundation www.epilepsyfoundation.org
American Epilepsy Society www.aesnet.org
National Institute for Neurological Disorders & Stroke www.ninds.nih.gov