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To learn more about this international grassroots effort, visit: http://www.purpleday.org/
Elizabeth Collins, RN-BC, MS, of The New Hampshire Department of Health and Human Services Grantee Team was recently recognized by The New Hampshire Chapter of the American Academy of Pediatrics (NHPS) for her extraordinary work to promote the health and welfare New Hampshire's children and families.

Recipients are vetted based on the following criteria:

1. Demonstrated service to a project or cause on behalf of children
2. Establishing community involvement to effect change in systems affecting children's issues
3. Proven commitment to children's issues
4. Local, state, or national champion of causes affecting children

Liz Collins is Title V Director for Children and Youth with Special Health Care Needs at Special Medical Services in NH. She has a Master's Degree in nursing leadership and a background in health planning and advocacy for special populations.

Liz's work at Special Medical Services has a strong focus on quality improvement, data integrity, family centeredness and sustainability. She has led efforts to improve overall access to care for CYSHCN, and has leveraged federal grant funding related to epilepsy, ease of use for Latino families and autism and other developmental disabilities.

Liz has partnered extensively with pediatric providers, recognizing the valuable role they play in the system of care for CYSHCN.

In 2008, she spearheaded the group that successfully wrote for a grant from the AAP Chapters to promote the open forum concept. This group developed and hosted two Open Forums dedicated to increasing awareness about screening, available tools, billing and incorporating families.

In 2012, Liz facilitated hosting two additional open forums. Liz is a member of both the Steering and Advisory Committee for NH's Pediatric Improvement Partnership, and has participated on many other advisories and councils in NH to insure that the needs of CYSHCN and their families are incorporated into state efforts. She has been a passionate supporter of families and youth as partners, insuring that the system of care is accessible and responsive.

**Congratulations Liz!**
MINUTES MATTER: IMPLEMENTING SEIZURE ACTION PLANS IN NEW HAMPSHIRE

The recent publication in Pediatrics “Rescue Medicine for Epilepsy in Education Settings” (Pediatrics, January 2016) is a welcome addition to the literature. The NH team has been working on this issue for some time, stressing the importance of seizure action plans and a more standardized approach to prolonged convulsions when they happen in the school setting, during transportation, field trips, athletic events, etc., and there is still work to do given the surprising diversity of practice and resources in northern New England. It is important to put this discussion in context, and to note that the move towards addressing seizures in the field has been a quiet revolution in medical practice in its impact on morbidity and mortality.

The New England Journal of Medicine (NEJM) report 2001 (Alldredge et al.) demonstrated better outcomes with emergency use of benzodiazepines in the field versus transporting the patient to a local emergency room before medications were given (standard care at the time). Further, the release of data on the efficacy and safety of rectal diazepam in 1998 and 2004, respectively (The North American Diastat Study Group, 1998, and Pellock, Drug Safety, 2004) shifted practice, resulting in improved outcomes and a dramatic decrease in episodes of status epilepticus requiring hospitalization or even emergency room visits. There has also been a proliferation of alternative approaches to management of seizures in non-medical settings (home, school), ranging from buccal instillation to intranasal routes and auto-injectable forms of administration, and including alternate medications (lorazepam, midazolam). The bottom line is that early administration of medication to stop seizures saves lives and can be done easily and safely, which means better outcomes and a bright outlook for the management of children with epilepsy.

There have now been millions of doses of benzodiazepine rescue given in the US, and a handful of respiratory depression that is more often the result of the seizure than the medication used to stop it. The risk of adverse effects (including respiratory depression) associated with administering a rescue medication are far outweighed by the risk of prolonged seizures (i.e. of not intervening in a timely manner).

A reasonable goal will be to have seizure action plans available for all children with epilepsy, and to consider tailoring plans to fit the circumstances and resources available in the various environments, especially school, where the children might be spending time. Most important to the success of any approach that requires a team that is spread out geographically is good communication/collaboration and being informed, spreading the care net generously wide so as to best take care of the children with epilepsy. It is a welcome new standard of care that will require additional elaboration on an individual basis, as “one size (protocol) does not fit all”.

Questions to consider:

Does the seizure action plan address the entire school day? The New Hampshire Department of Education, in Ed 311.02, defines the school day as “any time during the day, afternoon, or evening when a child is attending school or other school related activity.” If a student requires any medication during the school day, as defined, administration occurs under the direction of the school nurse.
MINUTES MATTER: IMPLEMENTING SEIZURE ACTION PLANS IN NEW HAMPSHIRE (CONT’D)

How will care be provided in the absence of the school nurse? It is unlikely that a school nurse will be present during every “school related activity” in which a student may participate. A student’s participation in school related activities is not contingent upon the availability of a nurse, nor can a parent be required to provide the care to support the student’s inclusion. The NH Board of Nursing has been asked to issue guidance on delegation within the school setting, and has affirmed that school nurses can delegate to non-licensed personnel. In NH, delegation is outlined in RSA 326-B Nurse Practice Act and Nur 404. RSA 326-B:29 protects nurses from disciplinary action based on the performance of the delegatee, if the nurse made the delegation in compliance with the chapter. It further provides protection to nurses from being forced to delegate when the nurse determines it is inappropriate to do so. Delegation is an important tool that promotes inclusion and safety, but it is not appropriate for all tasks, or all students.

What happens when 911 is called? As teams work together to establish action plans to ensure student safety, it is important to consider the safety net available. If a call is placed to 911, it isn’t the response time that matters; it is the response time to intervention. How soon before someone will be on scene who can administer medication to the patient? Know the answer to this question for school, and school-related activity locations.

What other local policies are in place? Local school boards and transportation companies may have specific policies regarding the administration of medication as well.

For additional information, please consult the FACETS of NH (Facilitating Access to Care for Epilepsy and Transition Success) Project pages on the NH Family Voices website.

These pages provide videos and materials for providers, family members, and school health providers, including sample action plans and communication tools, as well as specific resources regarding medication administration and the issue of delegation.
EPILEPSY TRAINING

The Epilepsy Foundation of New Jersey and its partners at the Epilepsy Foundation of Connecticut and Epilepsy Foundation of Northeastern New York have completed the training, Improving Accurate Diagnosis and Treatment of Epilepsy: A Training for Pediatric Practices, which occurred in each of their states. Attendees included pediatricians, nurses, and office staff in various pediatric practices.

Currently the partners are working with the same pediatric practices on the Maintenance of Certification (MOC) project in conjunction with Connecticut Children’s Medical Center. One of the goals of the project is to ask the pediatrician involved in the project to distribute informational epilepsy kits to every patient that they see with epilepsy. A sample of what is included in each kit can be found below.
INTEGRATION OF MENTAL HEALTH SCREENING MAY PREVENT SUICIDE IN EPILEPSY

Tatiana Falcone, MD, of the Cleveland Clinic, along with her colleagues, performed a research study that focused on children and youth with epilepsy (CYE). This data was recently shared at the 2015 American Epilepsy Society Annual Meeting in Philadelphia. During earlier studies, it was recognized that frequency of mental health issues among children with epilepsy, including depression, suicidal ideation, and suicidal or para-suicidal behavior was amplified.

A number of mental health screenings were performed from 2008 through 2015 for 400 CYE and the numbers were astounding. The detailed research results can be found here.

MIGRANT FARMWORKER OUTREACH

As in many states, rural areas are dedicated to agriculture. Farmworker contributions to harvesting and processing crops have a positive economic impact on the farms and communities where they work and live. Each year, approximately 45,000 to 50,000 migrant and seasonal farm workers are employed in Pennsylvania to assist in harvesting the Commonwealth’s fruit, vegetable, and mushroom crops. A report from The PA Center for Rural Pennsylvania indicated that there are a number of barriers to farmworkers meeting health care needs including: language, finances, insurance, transportation, literacy and lack of medical information. In an effort to provide information, support and training to children, youth, caregivers and farmworker support programs/staff, the Epilepsy Foundation of Western/Central Pennsylvania (EFWCP) has launched an outreach effort to contact these groups and offer needed information and services. Project staff have met with the PA Department of Education Migrant Education program staff to better understand need and access to farmworkers. Plans are being developed to visit residential camps and summer education programs. It is estimated that there are more than 5000 children residing in the worker camps. Project staff have also met with administrators of the Keystone Health Migrant Farmworker health clinics. Keystone is the sole grantee in Pennsylvania to provide health services to farm workers. Keystone operates four sites and serves 23 counties. Project staff intend to meet with site clinical staff and provide information, support and training.

Primary Programs that EFWCP collaborates with:

PA Department of Education – Migrant Education Program

Keystone Health Farmworker Program
EDUCATIONAL WEBINARS ON EPILEPSY

The Cleveland Clinic of Ohio has created a series of educational webinars for parents and family. Links to each video are provided below along with a summary of each.

**ADHD and Epilepsy:** In the first part of the webinar Dr Tatiana Falcone discusses the co-morbidity of ADHD in youth with epilepsy, the diagnostic issues and treatment. Dr Jane Timmons-Mitchell discusses Attention Deficit Hyperactivity Disorder (ADHD) and behavioral therapy treatment options. (Tatiana Falcone, MD, Child and Adolescent Psychiatrist, Assistant Professor, Jane Timmons-Mitchell, PhD, Clinical Child Psychologist).

**Anti-seizure medications and rescue seizure medications:** This webinar will address what every family should know about anti-seizure medications and rescue medications, how doctors choose which epilepsy medication to use, and what is new in the field of anti-seizure medications. (Elia Pestana Knight, MD, Pediatric Epileptologist, Assistant Professor).

**Anxiety and Epilepsy:** This webinar will cover why depression and anxiety are big problems for teens especially with epilepsy. It will tell how to recognize symptoms, what to do for your teen, how to know when depression and anxiety are more than usual concerns, and treatment available. It will also cover depression and the risk of suicide in epilepsy. (Tatiana Falcone, MD, Child and Adolescent Psychiatrist, Assistant Professor, Jane Timmons-Mitchell, PhD, Clinical Child Psychologist).

**Depression and Epilepsy in Children and Adolescents:** This webinar will cover why depression is a big problem for teens, and is more frequent for teens with epilepsy. It will discuss how to recognize depression, what to do for your teen, how to know when depression is more than a usual concern, and treatment that is available. It will also cover depression and the risk of suicide in epilepsy. (Tatiana Falcone, MD, Child and Adolescent Psychiatrist, Assistant Professor).

**Diagnosing Epilepsy:** This webinar will cover information about the EEG, how it provides information for the diagnosis of epilepsy, how to prepare a child for any EEG testing and the different types of EEGs (outpatient, Ambulatory, Video-EEG). Dr Elia Pestana Knight will provide information about the brain MRI, other imaging techniques, and information that they provide to the physicians. (Elia Pestana Knight, MD, Pediatric Epileptologist, Assistant Professor).

**Epilepsy Patient and Parent Perspective:** An in depth interview with a parent and her son, now in college, looking back at his journey with epilepsy. (Sammy Juhn, MSW, LSW, Denise Hagen, MSSA, LISW-S).

**Cognition in Children with Epilepsy:** Dr Patricia Klaas discusses when neuropsychological assessments may be helpful. She expands on behavioral concerns, possible accommodations and modifications that may be helpful as they relate to the diagnosis of epilepsy. (Patricia Klaas, PhD, Pediatric Neuropsychologist).

**Pediatric Psychogenic Non-Epileptic Seizures (PNES):** This webinar provides information of symptoms, treatments, frequency and risk factors associated with non-epileptic seizures. (Tatiana Falcone, MD, Child and Adolescent Psychiatrist, Assistant Professor, Jane Timmons-Mitchell, PhD, Clinical Child Psychologist).
EDUCATIONAL WEBINARS ON EPILEPSY (CONT’D)

**Taking Epilepsy to School:** This webinar will cover information about IEPs, (individual education plan) and how to interact with the school system and teachers. An overview will be given of the different forms that help physician and families to exchange information with the school system, including the Parent Questionnaire, the Seizure Action Plan and the Seizure Observation Form. There will be information about how to train the school staff (nurse, teachers, bus drivers, cafeteria and other staff) for a seizure event: when to share and how to share a diagnosis of epilepsy. (Tatiana Falcone, MD, Child and Adolescent Psychiatrist, Assistant Professor, Laura Neece-Baltaro, Epilepsy Educator).

**Transitioning Teens with Epilepsy:** Ready or not, your child with epilepsy will grow up. As he (or she) approaches adulthood, what do you need to do and who can help you and your child as they become an adult with epilepsy? This presentation provides answers and guidance to parents of teens who want to successfully move their son or daughter toward a happy and thriving adulthood with appropriate adult medical care for his or her epilepsy. It describes the gradual transition of medical care to the adult model and the steps in transitioning to adult lifestyles.

The presenter, Laura Neece-Baltaro is herself the mother of a young woman who had epilepsy throughout her teens. Ms. Neece-Baltaro has over 20 years of experience educating families of children with epilepsy on how they can live the healthiest and best lives possible. She has worked for three epilepsy organizations with epilepsy patients, their families, schools and epilepsy professionals. (Laura Neece-Baltaro, Epilepsy Educator).

**What Parents Need to Know about Epilepsy Surgery:** This webinar will describe the selection of patients for epilepsy surgery and the different types of epilepsy surgeries. It will also describe risks and benefits for possible surgery. (Elaine Wyllie, MD, Pediatric Epileptologist, Professor).

**When Your Child is Newly Diagnosed with Epilepsy:** A distinguished panel of presenters discuss the diagnosis of epilepsy. How the diagnosis is made, help to understand the diagnosis, how to treat it, and the importance of a seizure action plan. They discuss the importance of a support network such as: the neurologist, epileptologist, and primary care physician. Restrictions, safety issues, and strategies used for school partnership are provided. (Elaine Wyllie, MD, Pediatric Epileptologist, Professor, Tatiana Falcone, MD, Child and Adolescent Psychiatrist, Assistant Professor, Jane Timmons-Mitchell, PhD, Clinical Child Psychologist, Laura Neece-Baltaro, Epilepsy Educator).

Additional videos on When Your Child is Newly Diagnosed with Epilepsy:

- **Video 1** - Elaine Wyllie, MD, Pediatric Epileptologist, Professor
- **Video 2** - Tatiana Falcone, MD, Child and Adolescent Psychiatrist, Assistant Professor
- **Video 3** - Laura Neece-Baltaro, Epilepsy Educator
- **Video 4** - Jane Timmons-Mitchell, PhD, Clinical Child Psychologist
CONTINUING THE CHARGE TO BRING SPECIALTY EPILEPSY CARE TO PATIENTS ACROSS NEW MEXICO

In June 2014, Project ECHO launched the Child and Youth Epilepsy (CYE) TeleECHO Clinic to improve access to specialized care for children with epilepsy in New Mexico. At the time, there were roughly 10,000 children with epilepsy in New Mexico but only four pediatric neurologists and one pediatric epilepsy specialist, all located in Albuquerque. Patients were often unable to see their neurologist or epileptologist for months. For patients in distant towns and rural areas, travelling to Albuquerque for medical care was both time-consuming and expensive.

The expanded Epilepsy Across the Lifespan (EATL) TeleECHO Clinic, led by Kenneth W. Imerman, MD, works with providers nation-wide to provide telementoring and collaborative learning through didactics and case discussions. EATL allows for primary care physicians and other medical professionals to provide more epilepsy specialty care locally, ultimately improving access.

Dr Imerman maintains an informal, yet focused learning environment where colleagues can discuss the many facets of epilepsy, including diagnosis, pharmacological and surgical treatment plans, transition, and psychosocial concerns. Current learning partners include pediatricians, family practice physicians, nurse practitioners, physician assistants, school nurses, clinical pharmacists, epilepsy educators, UNM epilepsy fellows and pediatric neurology residents.

The EATL clinic welcomes anyone interested in caring for people with epilepsy. No cost continuing medical education credits are provided for participation at each session. For more information, please contact kimerman@salud.unm.edu.
UPCOMING CONFERENCES

Join the Canadian Paediatric Society and the American Academy of Pediatrics in Denver, Colorado, for the 7th International Meeting on Indigenous Child Health March 31 to April 2, 2017

The IMICH Planning Committee invites session/workshop proposals from anyone working with Indigenous populations, on any topic related to Indigenous child and youth health.

Submit your session proposal online at www.surveymonkey.com/s/IMICH2017Proposals

The deadline to submit proposals is May 9, 2016
Share this invitation and mark our conference dates in your 2017 calendar, TODAY

For more information, visit www.cps.ca/en/imich or www.aap.org/nach

The American Telemedicine Association’s (ATA) Annual Conference & Trade Show, the world’s largest and most comprehensive meeting focused on telemedicine, digital, connected and mobile health, will take place May 14-17, 2016, at the Minneapolis Convention Center.

To register go to: http://www.goata2016.com/

May 14- 17, 2016
Minneapolis Convention Center | Minneapolis, Minnesota
UPCOMING CONFERENCES (CONT’D)

**Association of Maternal & Child Health Programs**

Annual Conference

April 6-9, 2016
Washington, DC
Washington Marriott | Wardman Park

**MetaECHO™ 2016 Conference**

April 6-9, 2016
Albuquerque, NM
Hotel Albuquerque | Historic Old Town

**2016 National Conference & Exhibition**

October 22-25, 2016
San Francisco, CA

Conference Registration Opens on June 1<sup>st</sup>!
2016 Registration Rates Coming Soon!
For children and youth with epilepsy and their families, care coordination is critical. Care coordination should be a team- and family-driven process that improves family and health care practitioner experience. Need help promoting, implementing, or evaluating care coordination activities and measures? Technical assistance (TA) and support is now available through the National Center for Care Coordination Technical Assistance (NCCCTA):

- One hour of introductory TA regarding the Pediatric Care Coordination Curriculum, Care Coordination Measurement Tool and the Pediatric Integrated Care Survey
- Two additional hours of TA in the adaptation, implementation and evaluation of the aforementioned tools

Assistance and support through email, as necessary

Visit us for more information and links to the above tools

Contact us for TA or questions

Join the NCCCTA Community of Learners listserv

The NCCCTA is a partnership between the National Center for Medical Home Implementation and Boston Children's Hospital Integrated Care Program.

The mission of the NCCCTA is to support the promotion, implementation and evaluation of care coordination activities and measures in child health.
AAP RESOURCES

Pediatric Care Online™ is a practical and convenient resource integrating a full range of essential pediatric-specific clinical information and premier patient education content on seizure disorders.

This great resource can help you find:

- **Red Book® Online** – [Immunization in Children With a Personal History Of Seizures](#)
- **Pediatric Patient Education™** – [Parent and patient handouts specific to seizure disorders](#)
- **Point-of-Care Quick Reference** – [Chapters specific to Epilepsy and other seizure-related disorders](#)
- And much more!

Pediatricians: Visit [www.aap.org/pcotrial](http://www.aap.org/pcotrial) today to request your FREE 1-month trial, compliments of Mead Johnson Nutrition.

The AAP recently launched [Physical Developmental Delays: What to Look For](#), an interactive online tool, for parents of children ages 5 and under to use when they are concerned about their child’s motor development.

The tool lists physical activities by the age at which they are typically performed. If a parent is concerned that their child has not achieved a certain milestone or if there have been setbacks, parents can click on boxes included next to activity descriptions. This creates a list – with space for notes – that can be taken to the next pediatrician appointment.

Pediatricians who are approached by parents and caregivers with these concerns can refer to the AAP clinical report, [Motor Delays: Early Identification and Evaluation](#), which includes an algorithm to guide developmental surveillance and screening, red flags signaling a need for prompt referral and recommendations, including appropriate testing.
Digital Navigator

Lower costs, improve care, and help gain NCQA medical home recognition.

Transform your practice to the Patient- and Family-Centered Medical Home model of care. The Digital Navigator can help your practice

✓ Improve patient outcomes.
✓ Enhance quality and operational effectiveness.
✓ Improve system-wide financial performance.
✓ Plus much more...

Earn NCQA recognition with the Digital Navigator.

For more information visit digitalnavigator.aap.org today! Contact DNSales@aap.org to schedule a personalized demo of the Digital Navigator and receive a FREE Pediatric ICD-10-CM manual. A $73 value. Special offer expires on March 31, 2016.

American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™
The AAP Section on Neurology often collaborates with the AAP’s Private Payer Advocacy Advisory Committee (PPAAC), to advocate for optimal reimbursement for providers. Section experts review current medical policy by carriers such as Anthem, Blue Cross, United Health, etc. They have had great success impacting change to these policies to ensure their interpretation of medical necessity incorporates all effective treatment for epilepsy.

In 2015, Section experts reviewed the Anthem/Blue Cross Blue Shield policy on Genetic Testing for Epilepsy and wrote a letter from the AAP President that summarized studies and evidence demonstrating its effectiveness: that it provides significant improvements in clinical outcomes compared to available alternatives. They urged the carrier to reconsider their policy that genetic testing for epilepsy is investigational and should be considered medically necessary. As a result of this advocacy, Anthem changed their policy to include genetic testing for epilepsy as a covered service.

In June 2015, Section experts reviewed the Anthem medical policy on ambulatory EEG for home monitoring and observation or Inpatient video EEG, to ensure that their interpretation of the procedure’s medically necessity was comprehensive. Section experts recommended expanding medical necessity to include monitoring of active status epilepticus for inpatient EEG and benign epilepsy with centrotemporal spikes and juvenile myoclonic epilepsy for ambulatory EEG. Anthem revised its policy based on the input provided.