



DHHS Epilepsy Initiatives

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Background

▶ Epilepsy Workgroup

- Members: Operating Divisions of the Department of Health and Human Services
- Initiated: 2013
- Goal: Information sharing on programs/projects related to epilepsy



Office of the Assistant Secretary of Health

- ▶ Regional Health Administrator, in collaboration with, American Academy of Pediatrics, HRSA, and University of Kansas Medical Center
 - Kansas Project ECHO (Extension for Community Healthcare Outcomes) focuses on pediatric epilepsy
 - Telehealth/telemedicine technology, this project is a model for lifelong medical learning and collaborative practice that links front-line primary care clinicians with specialist care teams at university medical centers to manage patients who have chronic conditions requiring complex care.
 - Serves as a model of health care delivery and education to expand existing capacity to provide best practice for children and youth with epilepsy in rural and underserved areas



National Institutes of Health

- ▶ NIH Patient Reported Outcome Measurement Information System (PROMIS)
 - Provides access to adult and child patient-reported measures of symptoms, such as pain and fatigue, and aspects of health-related quality of life (HRQL)
- ▶ NIH Toolkit Resources:
 - Assessment of Neurological and Behavioral Function
 - HRQL Assessment tools (English and Spanish)
 - Provides new measures of cognitive, sensory, and motor function, as well as emotional health, for use in epidemiological, longitudinal and other large cohort studies including clinical trials.
 - Initial set of assessment tools has been validated for use with adults suffering from stroke, traumatic brain injury, and Parkinson's disease with and without depression.



National Institutes of Health

- ▶ Traumatic Brain Injury (TBI)
 - NIH supports a broad range of research
 - Preventing TBI
 - Understanding how TBI damages the brain
 - Identifying therapeutic or protective approaches, which will also be relevant to preventing, understanding, and treating post-traumatic epilepsy (PTE)
 - Efforts supported by grants to reduce incidence of TBI
 - Internet programs to train coaches, athletic staff, student athletes, parents, and school administrators on the recognition and management of sports concussions
 - Improved helmet design and incorporation of an impact alert system
 - Interactive multimedia program for children to enhance bicycle, pedestrian, wheeled sports safety skills.



Centers for Disease Control (CDC)

- ▶ Partnered with Epilepsy Foundation
 - Outreach to veterans addressing TBI and epilepsy
 - Partners Against Mortality in Epilepsy (PAME) conference addressing Sudden Unexpected Death in Epilepsy (SUDEP)
- ▶ Contribution to AJPH theme issue on stigma and combatting stigma
- ▶ CDC staff collaboration with AAN development of guidelines for management of mild (sports-related) TBI
- ▶ Support and collaboration with CDC Center for Global Health to improve antigen detection screening methods for cysticercosis and taeniasis.
- ▶ Prevention activities related to risk factors and causes of epilepsy, e.g., CNS infections, TBI, stroke, dementia, autism, and developmental disabilities, are conducted in separate centers, offices, and programs of CDC



Health Resources and Services Administration (HRSA)

- ▶ HRSA supported Institute for Healthcare Improvement Learning Collaborative for the systematic improvement of care for children and youth with epilepsy
- ▶ Grantees have worked together in multidisciplinary teams composed of healthcare professionals and parents to improve care processes.



Health Resources and Services Administration (HRSA)

- ▶ Funding initiative to enhance education of families and health professionals, particularly to build the knowledge base of pediatric primary care practitioners in diagnosing, treating, and supporting children and youth with epilepsy.
- ▶ Epilepsy Program grantees have implemented educational activities for families with focus on medical home, youth transition to adult system of care, development of seizure action plans, and partnering in quality improvement efforts.



DHHS Agencies

- ▶ Working together to improve cooperation and coordination across programs:
 - Newborn screening
 - Autism
 - Health Related Quality of Life
 - TBI
 - Clinical trial
 - Identifying therapeutic approaches
 - Prevention activities
 - Funding initiatives



Resources:

- NIH:
 - www.nihpromis.org/default
 - www.nihtoolbox.org/RFP/NeuroQol%20and%20the%20NIH%20Toolbox.pdf
 - www.nihtoolbox.org
- NIH-TBI
 - www.ninds.nih.gov/disorders/tbi/tbi.htm
- CDC
 - www.cdc.gov/epilepsy
- American Epilepsy Society
 - www.aesnet.org
- HRSA
 - www.mchb.hrsa.gov/programs/epilepsy/index.html
 - www.hrsa.gov/communitiesofpractice/AtaGlance/epilepsy.pdf

